

DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) A systematic review exploring therapist competence, adherence and therapy outcomes in individual CBT for children and young people. ; 2) How can we get better at recognising cases of fabricated illness? A service improvement project within a paediatric chronic fatigue service; 3) "I feel as though it will help me feel better, but it usually just makes things worse". The role of self-harm material on the internet.

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Research Portfolio Submitted in Part Fulfilment of the requirements for
the Degree of Doctorate in Clinical Psychology

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Doctorate in Clinical Psychology

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Abstracts

Critical Review of the Literature

Objective: Whilst the evidence base for Cognitive Behavioural Therapy (CBT) with children and young people is growing, the mechanisms through which these beneficial effects occur is still unclear. This systematic review seeks to appraise the relationship between therapeutic outcomes in CBT and therapist adherence and competence, within the child and adolescent literature. **Method:** A systematic review was carried out, with seven studies identified as meeting the inclusion criteria. **Results:** The literature is currently small and inconclusive. Amongst the studies reviewed there were inconsistent findings, with minimal-to-no effect sizes found between adherence, competence, and outcomes. **Conclusions:** The current paucity of research in this area means that conclusions are currently limited. The role and impact of adherence and competence on therapeutic outcomes remains unclear within individual CBT in a child population. This is comparable with the current adult literature, where findings also remain inconclusive. Further research avenues are discussed.

Keywords: CBT, adherence, competence, children, young people

Public health significance: Cognitive Behavioural Therapy has a growing evidence base for children. However, it is still unclear which mechanisms enable these beneficial effects. How well a therapist adheres to the model, and the competence with which they deliver the therapy, are two possible variables that may contribute to the outcome of therapy. This article reviews the state of the current literature.

Service Improvement Project

Fabricated or induced illness by another is rare and poorly understood. Whilst some of the difficulties recognising and managing it have been addressed in literature and guidelines, to date there has been no published consideration of fabrication within the context of chronic fatigue syndrome, which itself is often poorly understood and recognised. This study seeks to understand staff's experience and knowledge of fabricated or induced illness within a paediatric chronic fatigue setting. Whilst challenges in line with other health conditions are identified, additional challenges are also highlighted that may be unique to working within a chronic fatigue setting. Discussion of these and future improvements are considered.

Keywords: fabricated illness, chronic fatigue syndrome, paediatrics

Main Research Project

Objective: This novel study sought to examine the prevalence of online self-harm activity amongst those who self-harm and how this impacts on self-harming practices and related distress. **Method:** A small innovative experimental study (N=3) sought to look at real-time effects of viewing self-harm material online. A cross-sectional study of young adults (N=126) compared differences between those who view self-harm material online and those who do not. The impact of appraisal of online content was explored in both studies. **Results:** 48% of the sample reported currently viewing self-harm material online, with an additional 23% reporting having previously viewed such material. Stronger desire to self-harm and greater psychological distress was found amongst those who view self-harm material online. Due to the small sample size in the experimental study causal inferences about the role of viewing self-harm material online cannot be made. **Conclusions:** Findings suggest that viewing self-harm material online is common amongst those who self-harm and that those who view self-harm material online may have stronger urges to self-harm and greater psychological distress than those who do not view such material online, thus indicating a higher risk group.

Keywords: self-harm, self-injury, online, internet.

Public Health Significance Statement: This study suggests that amongst young adults who self-harm, those who view self-harm material online have stronger urges to self-harm and greater psychological distress than those who do not view such material online.

Word Count

Critical Review of the Literature	5,127
Service Improvement Project	5,430
Main Research Project	5,485
Executive Summary	1,092
Connective Narrative	2,333
Total	19,467

Table of Contents

Table of Figures and Tables	7
Acknowledgements	8
Chapter 1. Critical Review of the Literature	9
Abstract	10
Introduction	11
Method	15
Results	18
Discussion	24
References	29
Chapter 2. Service Improvement Project	33
Abstract	34
Introduction	35
Method	37
Results	39
Discussion	46
Recommendations	48
References	51
Chapter 3. Main Research Project	53
Abstract	54
Introduction	55
Ethical considerations	60
Study 1: Experimental Study	
Method	61
Results	64
Study 2: Cross-sectional study	
Method	69
Results	72
Discussion	79
References	83
Chapter 4. Executive Summary	90
Chapter 5. Connecting Narrative	95

Appendices

Appendix A. Journal of Consulting and Clinical Psychology Author Guidelines	103
Appendix B. Archives of Disease in Childhood Author Guidelines	105
Appendix C. Semi-structured interview script	106
Appendix D. Information sheet (SIP)	107
Appendix E. Consent form (SIP)	109
Appendix F. Debriefing sheet (SIP)	110
Appendix G. Presentation to service	111
Appendix H. Ethical approval (Study 1 and 2)	115
Appendix I. Risk assessment	117
Appendix J. Information and consent (Study 1 and 2)	120
Appendix K. Debriefing information (Study 1 and 2)	127
Appendix L. Recruitment poster	130
Appendix M. Visual analogue scale of desire to self-harm	131
Appendix N. Internal consistency	132
Appendix O. Rating of appraisal of online self-harm material viewed	133
Appendix P. Example of online advertisement	134
Appendix Q. Qualitative information on websites viewed and search terms	135
Appendix R. Power analyses: cross-sectional study (study 2)	137
Appendix S. Qualitative analysis plan	138
Appendix T. Statistical analyses and assumptions	139
Appendix U. Demographic information for collapsed groups	142
Appendix V. Demographic information	143
Appendix W. Correlation matrix	144
Appendix X. Visual depictions of themes from thematic analysis	145

Figures

Figure 1.1	PRISMA diagram of search strategy	17
Figure 3.1	Procedure of experimental study	63
Figure 3.2	Desire to self-harm pre-, during, and post-viewing online self-harm material	66
Figure 3.3	Loneliness pre- and post-viewing self-harm material online	66
Figure 3.4	Recovery encouragement pre- and post-viewing self-harm material online	67
Figure 3.5	Negative affect pre- and post-viewing self-harm material online	67
Figure 3.6	Positive affect pre- and post-viewing self-harm material online	68

Tables

Table 1.1	Search terms	15
Table 1.2	Inclusion and exclusion criteria	16
Table 1.3	Study characteristics	19
Table 1.4	Study outcomes	20
Table 2.1	Themes from thematic analysis	40
Table 3.1	Four-function model of non-suicidal self-injury	57
Table 3.2	Study 1 Research questions and hypotheses	61
Table 3.3	Ratings of online self-harm material viewed	65
Table 3.4	Study 2 Research questions and hypotheses	69
Table 3.5	Descriptive statistics	73
Table 3.6	Descriptive statistics for main measures by group and for whole sample, groups compared using t-tests	74
Table 3.7	Mediational analysis	76
Table 3.8	Themes arising from content analysis	77

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Chapter 1. Critical Review of the Literature

A systematic review exploring therapist competence, adherence and therapy outcomes in individual CBT for children and young people.

Hannah Rapley

Supervisor: Dr Maria Loades

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Author guidelines Appendix A

Abstract

Objective: Whilst the evidence base for Cognitive Behavioural Therapy (CBT) with children and young people is growing, the mechanisms through which these beneficial effects occur is still unclear. This systematic review seeks to appraise the relationship between therapeutic outcomes in CBT and therapist adherence and competence, within the child and adolescent literature. **Method:** A systematic review was carried out, with seven studies identified as meeting the inclusion criteria. **Results:** The literature is currently small and inconclusive. Amongst the studies reviewed there were inconsistent findings, with minimal-to-no effect sizes found between adherence, competence, and outcomes. **Conclusion:** The current paucity of research in this area means that conclusions are currently limited. The role and impact of adherence and competence on therapeutic outcomes remains unclear within individual CBT in a child population. This is comparable with the current adult literature, where findings also remain inconclusive. Further research avenues are discussed.

Keywords: CBT, adherence, competence, children, young people

Public health significance: Cognitive Behavioural Therapy has a growing evidence base for children. However, it is still unclear which mechanisms enable these beneficial effects. How well a therapist adheres to the model, and the competence with which they deliver the therapy, are two possible variables that may contribute to the outcome of therapy. This article reviews the state of the current literature.

A systematic review exploring therapist competence, adherence and therapy outcomes in individual CBT for children and young people.

Although increasing evidence continues to emerge in support of the efficacy of Cognitive Behavioural Therapy (CBT), the mechanisms through which it exerts its beneficial effects are generally not well understood (Kazdin, Whitley, & Marciano, 2006; Webb, DeRubeis, & Barber, 2010). Effectively assessing and understanding these underlying mechanisms is crucial to the success of expanding CBT effectiveness, training, and service provision, in order to disseminate further evidence-based practice into routine care.

Researchers have long hypothesized about a number of different ‘active ingredients’ that may be responsible for the therapeutic improvements observed in CBT. Orlinsky and Howard defined process research as “everything that can be observed to occur between and within the patient and therapist during their work together” (1986, p. 311-312). Research investigating these process variables hopes to understand which elements and processes in an intervention contribute to positive treatment outcomes. By understanding these treatment factors, researchers and clinicians can modify interventions, thus providing optimum doses of active ingredients and minimizing inert elements, with the ultimate goal of improving treatment efficacy (Kazdin et al., 2006). Without rigorous assessment, and understanding of adherence to treatment protocols and the competency with which they are delivered, the internal validity of interventions can be compromised. This therefore limits clinicians’ and researchers’ ability to attribute client outcomes to the treatment they received. Unfortunately, adequate assessment of treatment integrity is not the norm in outcome trials, particularly in youth psychotherapy. Perepletchikova, Treat and Kazdin (2007) found that only 3.5% of studies of youth and adult psychotherapy reviewed, met their criteria for adequate implementation and reporting of treatment integrity procedures.

Adherence refers to the extent to which a therapist delivers the intervention and techniques as prescribed by the treatment manual or model (Perepletchikova & Kazdin, 2005; Waltz, Addis, Koerner, & Jacobson, 1993). Measures of adherence usually assess how frequently or how thoroughly therapists employ particular techniques. It constitutes a major component of treatment integrity, and is essential to establish experimental validity. Whilst

the theoretical importance of adherence in psychotherapy has been discussed at length, the level of impact on treatment outcome remains unclear (Emmelkamp et al., 2014).

Therapist competence is defined as the extent to which a therapist implements an intervention skilfully and appropriately for the patient in question (Barber et al., 2006). Although adherence and competence are related constructs, they are conceptually distinct. Put simply; therapist adherence refers to ‘how much’ of the therapy the therapist employs, and therapist competence refers to ‘how well’ the interventions are executed (Shaw & Dobson, 1988). Muse and McManus (2013) identified that in practice there can be much overlap between the two constructs. Moderate to high correlations (ranging from $r=0.5$ to $r=0.85$) have been found between adherence and competence (e.g. Barber, Krakauer, Calvo, Badgio, & Faude, 1997; Barber, Liese, & Abrams, 2003; Carroll et al., 2000), which indicates the difficulty of disentangling these two constructs. Some authors have stated that in order for therapists to be competent in a therapeutic modality, they must be adherent to the intervention protocol; such that they argue adherence is a prerequisite for the competent delivery of an intervention, whilst adherence provides no guarantee of competence (Waltz et al., 1993), thus meaning that adherence may be necessary but not sufficient for attaining competence.

Research examining therapist adherence and/or competence has almost exclusively employed observational rather than experimental methods. Hogue, Liddle and Rowe (1996) identified three general methods for assessing adherence in therapy: Quality control measures can be employed prior to conducting therapy, e.g. through training and regular supervision. Secondly, notes can be reviewed for treatment elements, or through therapist self-report. Thirdly, and indicated as the best means of capturing treatment adherence, is observational review of therapists’ in-session behaviour. Most commonly, trained raters code one-or-more video or audio-taped therapy sessions using measures of adherence. Similarly, there are several methods for evaluating competency, including observer, supervisor and therapist ratings. Waltz and colleagues (1993), recommend that the stage of therapy, session number, and progress-made-thus-far should be considered when rating therapist competence. These methods are labour intensive and thus expensive (Horvath, Del Re, Flückiger, & Symonds, 2011), which may in part explain the lack of regular monitoring of these variables in outcome research. However, it is difficult to draw conclusions about the efficacy of CBT protocols unless it can be ensured that protocols are adequately and competently delivered (Waltz et al., 1993; Weck, Grikscheit, Jakob, Höfling, & Stangier,

2015). Thus, accurate and rigorous measurement of these variables is imperative. Without this, successful dissemination of treatment provision and therapist training is not viable (Muse & McManus, 2013).

Despite the difficulties of conducting research into process variables, a body of research exists examining process variables for CBT within an adult population. A study of 1,247 adult patients and 43 therapists within primary care found little support for an association between competence in CBT and client outcome (Branson, Shafran, & Myles, 2015). However, significantly more patients of the most competent therapists demonstrated reliable improvements in their symptoms of anxiety than would be expected by chance alone. Within a study of adults with anxiety and panic disorder, therapist competence and adherence in the early stages of therapy was associated with better outcomes amongst those with panic disorder (Haug et al., 2016). Amongst those with social anxiety, lower therapist competence and adherence was associated with higher drop-outs from therapy. The authors conclude that therapist competence, adherence and alliance may have independent contributions to the outcome of CBT for anxiety disorders, but in different phases of treatment.

A comprehensive meta-analysis of 36 studies in the adult literature found huge variability in the adherence-outcome and competence-outcome relationships, with aggregate estimates of effect sizes being very close to zero (Webb et al., 2010). Neither the adherence-outcome ($r=0.02$) nor the competence-outcome ($r=0.07$) effect size estimates were found to be significantly different from zero, thus suggesting that neither adherence nor competence were significant predictors of treatment outcomes. Additional analyses showed that when only interventions for depression were considered, a significant correlation between competence and outcome emerged. No significant effect was found for adherence. Another meta-analysis (Zarafonitis-Muller, Kuhr, & Bechdorf, 2014) found a small but significant effect of therapist competence on therapeutic improvement ($r=0.24$) when looking across a range of disorders, and a moderate effect ($r=0.38$) when depression interventions were considered on their own. No significant results were found for the influence of adherence to protocol on treatment outcome. Thus, these meta-analyses find minimal support for a role of adherence or competence on therapy outcomes. However, findings from the second study suggest that a competent delivery of cognitive-behavioural techniques may contribute to therapeutic improvements, whereas solely manual guided adherent implementation of CBT does not appear to have a significant impact on therapeutic outcomes.

As indicated above, there is significant inconsistency in the literature. It has been hypothesised that this may be due to study limitations and measurement difficulties associated with process variables (Feeley, DuRubeis, & Gelfand, 1999; Webb, Auerbach, & DeRubeis, 2012). These have included; non-optimal research designs, use of audio not video recordings, use of undergraduate not professional raters, and small sample sizes.

CBT process research in children and young people is significantly smaller and has lagged behind the adult literature. Only a handful of studies have examined adherence-outcome or competence-outcome relationships in CBT for young people. A review by Webb and colleagues (2012) summarized the evidence for outcome and process variables in CBT for adolescent depression. They concluded that whilst a growing body of research supports the efficacy of CBT for adolescent depression, the mechanisms through which it is beneficial remain unclear. It is important that process research within CBT focuses independently on children and young people, due to likely differences in developmental factors such as cognitive functioning, social development and emotional skills (Kingery et al., 2006). Assumptions cannot therefore be made that results from adult process research is directly transferable to a child and adolescent population.

The present review

The evidence for the role of adherence and competence on therapy outcomes is mixed in adults (Webb et al., 2010), and much less attention has been paid to these mechanisms within a child population (under 18 years old). This systematic review seeks to identify what is understood about these mechanisms in CBT with children. Does the literature suggest a similar picture to that currently seen with adults? Or do these mechanisms work differently in this population? Is there currently enough information for conclusions to be drawn?

This systematic review aims to summarise and scrutinize the literature available on adherence and competence process research in relation to therapy outcomes in individual CBT for children and young people, in order to synthesise the state of the evidence base, and illuminate areas for further research. Put simply, this review aims to answer the question; is therapist adherence and therapist competence linked to therapy outcomes in CBT for children and young people?

Method

Search strategy

The procedures were informed by accepted systematic reviewing guidelines (Khan, Ter Riet, Glanville, Sowden, & Kleijnen, 2001; Moher, Liberati, Tetzlaff, & Altman, 2009). The following databases were searched from the earliest available listing to 28th July 2016: PsycINFO, Embase and PubMed. The first 50 pages of Google Scholar were screened for additional articles. Key-word search terms included; 1) cognitive-behavioural therapy 2) children and young people 3) therapist adherence, and 4) therapist competence. Full search terms can be found in Table 1.1.

Table 1.1

Search terms

	CBT OR “Cognitive Behaviour* Therapy”
AND	Child* OR “young people” OR “young person” OR adolesc* OR p?ediatric
AND	Therapist AND competen* OR adherence OR fidelity

Eligibility criteria and study selection

Studies were included if participants were under the age of 18, the intervention consisted of individual CBT, and contained psychometrically validated measures of therapist adherence and/or competence, and a measure of therapeutic outcome. They were excluded if participants were over the age of 18, the intervention was less than three sessions of CBT and if the intervention was group-based. The searches were restricted to English-language publications. Full inclusion and exclusion criteria can be found in Table 1.2.

Table 1.2

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<i>Studies involving:</i>	<i>Studies involving:</i>
Participants under the age of 18	Adult participants
CBT intervention (minimum three session)	Alternative models of intervention. CBT interventions with less than three sessions.
Purpose was to treat a mental health disorder	Purpose was not to treat a mental health disorder.
Individual CBT	Group CBT
Measure of symptom change on a psychometrically validated scale or standardised interview, pre- and post-intervention.	
A psychometrically validated measure of therapist adherence and/or therapist competence.	
Articles published in English.	Articles not published in English.

The initial search returned 237 articles. Once duplicates were removed 212 articles remained. Abstracts and titles were screened for relevance by the lead author. From this, 47 articles were taken through to the full-text screening phase. Here, full texts were screened by the lead author. A random sample of 20% of these articles were additionally screened by a 2nd reviewer. This inter-rater reliability returned 100% agreement for inclusion/exclusion. Any discrepancies during this process were resolved through discussion with supervisor. Following this, seven articles were found to meet the inclusion criteria and were included in this systematic review. See Figure 1.1 for PRISMA diagram of search strategy (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

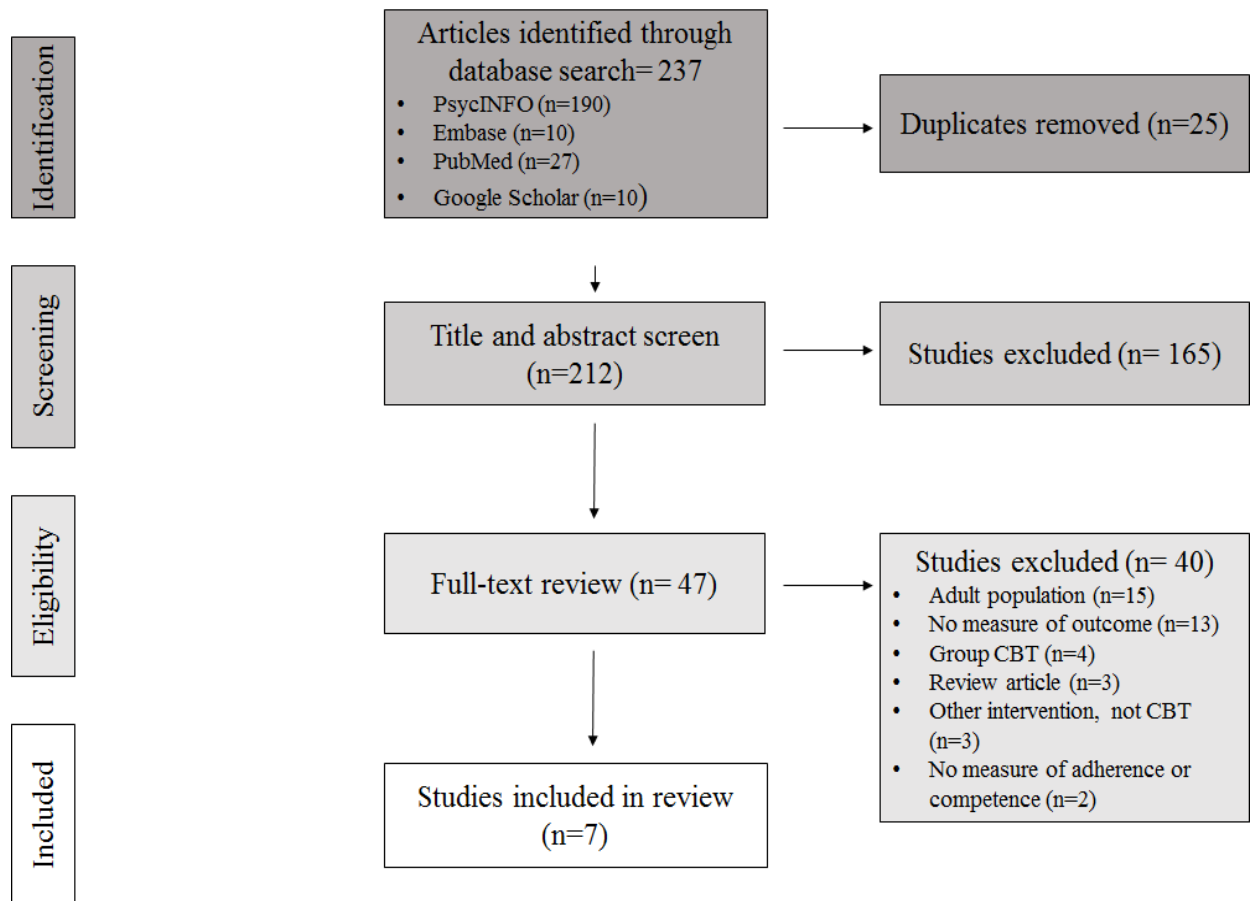


Figure 1.1 PRISMA diagram of search strategy (Moher, Liberati, Tetzlaff, Altman, et al., 2009).

Data extraction and analysis plan

Data regarding the sample characteristics, composition of the interventions, adherence and competence measures, outcome measures, and indicators of efficacy, such as statistically and non-statistically significant outcomes were extracted from the seven articles. If sufficient data was available, a meta-analysis would have been conducted. However, in the absence of sufficient comparable data, a systematic review was undertaken.

Results

Description of the included studies

The final review included seven studies. Of these seven studies, the data from five studies was from RCTs, with the other two studies being controlled observational designs. Participants ranged from 5-17 years old, with three studies containing adolescents, and the remaining involving younger children. All studies containing a mix of genders. Ethnicity was reported in all studies, with Caucasian and African American participants in the majority. A range of socio-economic statuses were indicated. Five studies were from the USA, and one from the UK (Creswell et al., 2010) and Holland (Liber et al., 2010). Limited demographic information was provided in one study (Creswell et al., 2010). The included studies addressed several different clinical problems. Four of the interventions were designed to treat anxiety disorders (Creswell et al., 2010; Ginsburg, Becker, Drazdowski, & Tein, 2012; Liber et al., 2010; Podell, 2011), two substance abuse (Chinchilla, 2007; Hogue et al., 2008), and one trauma (Cohen et al., 2016). Some of the interventions used named manualised treatment protocols, e.g. Coping Cat (Podell, 2011), and the FRIENDS programme (Liber et al., 2010). Others stated using CBT or Trauma-Focused CBT (Cohen et al., 2016). Table 1.3 summaries characteristics of the included studies.

Table 1.3
Study characteristics

Author (Year)	Design	Number of participants for CBT	Mean age, (% male)	Primary target of intervention	Intervention	No. of sessions
Chinchilla, (2007)	RCT	64	15, range 13-17, (80%)	Substance abuse	CBT	Mean = 12.12
Cohen et al. (2016)	RCT	81 (32 completed)	15.1, (47%)	Trauma	TF-CBT	Mean = 10.2
Creswell et al. (2010)	Observational	52 (41 completed)	Range 5-12	Anxiety disorders	Guided CBT administered through parent.	4 (plus four 15 min phone session)
Ginsburg et al. (2012)	RCT	17	11.12, (30%)	Anxiety disorders	CBT	Mean = 7.29
Hogue et al. (2008)	Controlled	62	15.5, (81%)	Substance abuse	CBT	Mean = 12.3
Liber et al. (2010)	RCT	24	10.72, range 8-12, (58%)	Anxiety disorders	FRIENDS programme	14 (10 with child, 4 with parent)
Podell, (2011)	RCT	139	10.74, range 7-17, (48.3%)	Anxiety disorders	Coping Cat	14

Table 1.4
Study outcomes

Author (Year)	Outcome measures	Measure of adherence	Measure of competence	Coding	No. of sessions coded	Conclusions
Chinchilla, (2007)	R-CBCL* YSR	Contextual Assessment of Therapist Competence (CATC-CBT)		Observer rated	5 sessions	No significant relationships.
Cohen et al. (2016)	UCLA PTSD RI MFQ	TF-CBT Fidelity Checklist	None	Self-rated by therapist	Every session	Adherence-outcome relationship not examined. No conclusion can be drawn.
Creswell et al. (2010)	ADIS-IV CGI-I SCAS CAIS MFQ DASS	Manual based measure	None	Observer rated	14% of sessions were coded	Adherence-outcome relationship not examined. No conclusion can be drawn.
Ginsburg et al. (2012)	ADIS-IV CGI-I,S	Treatment Adherence and Therapist Competence (TATC)		Observer rated	2 sessions	Greater session structure and competence implementing this component was associated with better treatment outcomes.
Hogue et al. (2008)	PEI CBCL YSR	Therapist Behaviour Rating Scale – Competence		Observer rated	5 sessions	Main effect for adherence on marijuana use (d=.44) and on parent reported externalizing (d=.37). Curvilinear main effect of adherence on parent-reported internalizing symptoms (d=.40).
Liber et al. (2010)	ADIS-IV CBCL MASC	The Australian Treatment Adherence Protocol for the FRIENDS programme	None	Observer rated	2 sessions	No sig relationship between adherence and child or parent reported outcomes.

Podell, (2011)	CGI – I,S CBCL MASC CGAS	CBT Checklist	Supervisor Rating Form	Supervisor rated	1 measure of competence. Adherence unclear.	Therapist treatment integrity was a significant predictor of outcome on parent-rated measures. Therapist competence was sig predictor of child-reported outcomes.
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Note: R-CBCL = Revised Behaviour Checklist; YSR = Youth Self Report; UCLA PTSD RI = UCLA PTSD Reaction Index; MFQ-Short = Mood and Feelings Questionnaire, Short Version; ADIS-IV = Anxiety Disorders Interview Schedule for Children/Parents; CGI-I,S = Clinical Global Impression – Improvement subscale, Severity subscale; SCAS = Spence Child Anxiety Scale (Child & Parent report); CAIS = Child Anxiety Impact Scale; DASS = Depression Anxiety Stress Scale; PEI = Personal Experience Inventory; MASC = Multidimensional Anxiety Scale for Children; CGAS = Global Assessment Scale for Children.

Qualities of studies

Study quality was assessed using the Critical Appraisal Skills Programme guidelines (Critical Appraisal Skills Programme, 2017), which were chosen to provide a descriptive framework to assess study quality and rigour. Study quality varied. Five of the studies were published in peer-reviewed journals, however two were from unpublished doctoral theses (Chinchilla, 2007; Podell, 2011), and therefore had not been subject to peer scrutiny.

Varying attention and detail was paid to the measurement of adherence and competence. Four of the studies measured both adherence and competence (Chinchilla, 2007; Ginsburg et al., 2012; Hogue et al., 2008; Podell, 2011), and three measured just adherence (Cohen et al., 2016; Creswell et al., 2010; Liber et al., 2010). This variability was further compounded as all studies used different measures of adherence and competence, except two studies where different versions of the same measure were used (Chinchilla, 2007; Hogue et al., 2008). Adherence measures rated the presence or absence of CBT treatment components to assess if the intervention was delivered as prescribed, these were rated using checklists or Likert scales. Competence measures included assessments of therapist characteristics, qualities and how well clinical skills were employed. Observer-rated Likert measures were used. However, whilst measurement approaches were similar across studies, there was little consistency in the outcome measures used.

Psychometric properties of adherence and competence measures were reported sporadically. Often the measures had been created for the study at hand, or previous associated studies (Chinchilla, 2007; Cohen et al., 2016; Creswell et al., 2010; Ginsburg et al., 2012). The most robust reporting of psychometric properties came from Hogue et al., (2008), where intra-class correlation coefficients (ICCs) are discussed, with the measure showing ‘good-to-excellent’ interrater reliability for adherence, and ‘fair-to-poor’ for competency, based on Cicchetti’s (1994) criteria. Otherwise reporting of psychometric properties was insufficient.

In six of the studies, ratings of adherence and/or competence were completed by observational raters, one study included a self-rated measure of adherence by the therapist (Cohen et al., 2016). In most studies, multiple ratings of adherence and competence were completed. Two studies, (Chinchilla, 2007; Hogue et al., 2008) aimed to review five sessions of an intervention (two from the beginning, and three sessions from later in therapy). Two other studies collected adherence and/or competence measures on two occasions, in the

earlier and then later stages of therapy (Ginsburg et al., 2012; Liber et al., 2010). The remaining three studies used less rigorous collection of measures, details of which can be found in Table 1.4.

All studies, except one (Ginsburg et al., 2012), detailed the training of both therapists and independent raters. Quality control measures employed to ensure that both therapists and independent raters are trained to a significant level of reliability are discussed.

In studies where randomisation was present, details of these processes were documented, and raters were blinded to conditions.

Outcomes of studies

Whilst all of the included studies contained measures of outcomes and adherence and/or competence, two studies contained no direct analysis of the relationship between adherence and/or competence to therapy outcomes (Cohen et al., 2016; Creswell et al., 2010). These studies were therefore unable to contribute to the research question of this systematic review.

The overall picture of findings from the remaining five studies is limited and inconclusive. A well-designed and thorough study by Hogue et al., (2008) found a small-to-medium effect ($d=0.44$) of adherence on reduction of marijuana usage, and a similar effect size ($d=0.37$) was found between adherence and parent reported externalizing symptoms. However, this latter effect was only analysed across both the CBT and multidimensional family therapy (MDFT) groups, so must be treated with caution, as its' effects cannot be attributed to CBT alone. Hogue and colleagues also analysed curvilinear effects within their data. They found a curvilinear small-to-medium effect ($d=0.40$) of adherence on parent-reported internalizing symptoms, thus suggesting that moderate levels of adherence predicted the lowest internalizing scores, whereas low and high levels of adherence predicted relatively worse internalizing scores. Again, this analysis was conducted across both the CBT and MDFT conditions.

Podell (2011) found that adherence was a significant predictor of outcome on parent-rated outcome measures only, whilst therapist competence was shown to be a significant predictor of child-reported outcomes. However, limitations in terms of measurement rigour should be considered: Therapist competence ratings were rated once per patient by a

supervisor at the conclusion of the intervention, and the frequency of measurement of adherence is unclear.

Ginsburg and colleagues (2012) reported that greater session structure and greater competence implementing these components was associated with better treatment outcomes. However, no effect sizes are provided and therefore limited conclusions can be drawn.

Two studies found no significant relationships between adherence and/or competence and therapeutic outcomes (Chinchilla, 2007; Liber et al., 2010).

Discussion

This systematic review analysed findings from seven studies in which therapist adherence and/or competence was examined in relation to therapy outcomes, amongst clinical samples of children receiving individual CBT. Support for a role for adherence or competence on therapeutic outcomes was limited and inconsistent. Study quality and the lack of literature mean that currently limited conclusions can be drawn.

Of the seven studies included, two did not investigate the relationship between adherence and/or competence and outcome, and therefore were redundant for answering the research questions posed by this review. The remaining five studies presented a mixed and inconclusive picture of the relationship between adherence and outcome, and competence and outcome in CBT for children and young people. Whilst two studies identified no significant relationships between adherence, competence and outcome, a range of significant effects were found across the others. Inconsistent effects were found on some measures, but not others, e.g. parent versus child measures, and internalising versus externalising symptoms (Hogue et al., 2008; Podell, 2011). It is unclear whether this variability is detecting true differences in effects, or instead reflects limitations of measurement. Quality of the included studies was markedly varied. Studies varied in terms of measures of competence and adherence used, and the robustness and frequency with which they were used. Additionally, the included studies were focused on a range of different clinical disorders, thus all studies were seeking to adhere to a different intervention programme or manual. This is a significant confound, and is likely to complicate identifying true effects. Thus, conclusions drawn must be tentative, as effects may vary across disorders and protocols. Future studies should seek to control for this variability.

Overall the findings from this small collection of studies are mixed and inconclusive. Due to the small number of studies, the varied outcomes and effect sizes, and variability in methodology, it is difficult to draw valid and reliable conclusions about the relationship between adherence and competence and outcomes, in youth CBT.

Whilst the adult literature is more developed with a greater number of studies, similar inconsistent effects have been found. A substantial meta-analysis by Webb and colleagues found large variability between adherence-outcome and competence-outcome effects, with aggregate effect sizes not being significantly different from zero (Webb et al., 2010). Thus, suggesting an inconclusive picture across both adult and child literature. It has yet to be explored if the effects of adherence and competence on therapeutic outcomes vary with the developmental trajectory of childhood.

Interpretations about the lack of a significant relationship between outcome and adherence and competence, both within this review, and within the adult literature, are limited due to substantial methodological variability in the assessment of adherence and competence (Huppert, Barlow, Gorman, Shear, & Woods, 2006). Firstly, measures of adherence and competence are often newly created for the purposes of a specific trial, with limited reliability and validity (Pereplechikova & Kazdin, 2005; Webb et al., 2010). Adherence and competence are frequently conceptualised as stable characteristics within a therapist and within a treatment. This is reflected by these variables commonly being assessed at a single time-point in the majority of studies (Horvath et al 2001; Webb et al 201). However, adherence and competence likely vary between sessions for the same patient, as well as across different patients of the same therapist (Boswell et al., 2013). It is therefore crucial that multiple sessions, across the span of the intervention should be coded in order to obtain reliable ratings of adherence and competence (Webb et al., 2010). In this review attempts were made in all but one study to obtain at least two or more ratings of adherence and competence. However, often ratings are only based on assessments of single sessions (Webb et al., 2010).

Secondly, another methodological limitation may be due to the therapists selected to take part in research studies. In RCTs therapists are usually selected, trained and monitored to high levels of competence and adherence. It is therefore likely that this may restrict the range of scores, thus creating a ceiling effect, which may make it difficult to determine the true relationship between therapist competence, adherence and outcome. Only one study

reviewed (Chinchilla, 2007) reported that competence and adherence scores were not skewed by a ceiling effect.

Thirdly, when considering adherence to protocols, the importance and utility of treatment manuals can be controversial, particularly in respect to how rigidly, or adherently, they should be implemented. There is little consensus regarding what constitutes a sufficient versus suboptimal level of adherence necessary to influence or even promote desired outcomes (Haug et al., 2016). Some studies suggest that high levels of adherence indicate therapist rigidity, which may undermine the development of an effective therapeutic relationship (Castonguay, Goldfried, Wiser, Raue, & Hayes, 1996), and prevent the competent delivery of an intervention. More recently some researchers have investigated whether a curvilinear relationship between adherence and outcome exists; in that low and very high adherence may predict worse treatment outcomes than a moderately adherent therapist. Barber et al., (2006) found a curvilinear adherence-outcome effect in adults, where moderate adherence predicted greatest improvement in drug use and depressive symptoms, when compared to high and low adherence. A similar curvilinear effect of adherence was found on one outcome measure in the included study by Hogue and colleagues (2008). Thus moderate adherence may represent a balance between treatment protocol and clinical flexibility, which therefore may be related to the concept of therapist competence (Stratton, 2011). The concept of therapist responsiveness has been offered as a possible explanation of the variations in findings in process research (Stiles, 2009). This refers to the idea that therapists adapt their behaviour to the unfolding context of treatment, including patient behaviours and characteristics. It infers that therapists, on the whole, do not deliver predetermined levels of an intervention, but instead are responsive to the emerging context in therapy (Webb et al., 2012).

Therapist process variables, such as therapist adherence and competence, do not operate in a vacuum. It is likely that the relationship of process variables to outcomes may be moderated by a range of other therapist and patient variables. Webb et al. (2010) indicated that therapeutic alliance could be a moderating variable, which should therefore be considered in future studies. Therapeutic alliance is the quality and nature of the bond and relationship between the therapist and the client. The adult literature has found it to be a relatively consistent predictor of outcome across a variety of treatment modalities (Martin, Garske, & Davis, 2000). However, whilst a minority of studies have investigated such process variables together, the variables have mostly been examined in isolation from one

another. Thus the relationship remains unclear. In one of the few studies to investigate alliance alongside other process variables, Weck et al., (2015) found a moderating effect of adherence with alliance on outcome, thus indicating that the better the therapeutic alliance, the stronger the effect of adherence on treatment outcome. They also found that alliance mediated the relationship between therapist competence and outcome. No studies have yet looked at this within a youth population.

This review provides a systematic appraisal of the literature focused on the relationship between therapy outcomes and therapist adherence and/or competence. Its' strengths lie in the rigorous and transparent procedures followed, but the utility of the review is limited by the current small evidence base identified. However, this therefore highlights the paucity of research in this area and hopefully can encourage future areas of development.

Future process-outcome studies within youth CBT should consider the possible curvilinear effect of adherence and ensure this is investigated in future studies. If further marginal or inconsistent effects are found, it will be important to acknowledge and measure multiple sources of variability which may affect process variables and their relationships to change (Perepletchikova & Kazdin, 2005). It is likely that adherence and competence are complex constructs that are influenced by a range of interacting variables (Boswell et al., 2013). Future research should focus on identifying factors that both facilitate and hinder treatment fidelity, particularly therapeutic alliance and responsiveness.

Conclusions

With an increasing emphasis on dissemination of evidence-based practice, and value for money, it is important that researchers seek to understand the effects of process variables on therapeutic outcomes to maximise the effectiveness and efficiency of evidence-based therapy in routine clinical practice. This review highlights that the literature on process variables, specifically therapist adherence and competence as components of treatment integrity, in individual CBT for children and young people is currently sparse, with few significant findings or agreement. It is therefore difficult to make substantial recommendations for CBT practice, based on the available youth process literature. There is a need for future well-designed process studies in youth CBT, in order to understand the 'active ingredients' of this approach, to be able to refine protocols, and maximise treatment effectiveness and training; ultimately improving clinical practice and outcomes. The

prediction of therapy outcome from therapeutic processes is most likely to be a complex relationship, influenced by a multitude of factors. By identifying such variables, more “effective and efficient CBT interventions” (Webb et al., 2012, p. 663) can be delivered for children

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Chapter 2. Service Improvement Project

How can we get better at recognising cases of fabricated illness? A service improvement project within a paediatric chronic fatigue service.

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Abstract

Fabricated or induced illness by another is rare and poorly understood. Whilst some of the difficulties recognising and managing it have been addressed in literature and guidelines, to date there has been no published consideration of fabrication within the context of chronic fatigue syndrome, which itself is often poorly understood and recognised. This study seeks staff's experience and knowledge of fabricated or induced illness within a paediatric chronic fatigue setting. Whilst challenges in line with other health conditions are identified, additional challenges are also highlighted that may be unique to working within a chronic fatigue setting. Discussion of these and future improvements are considered.

Keywords: fabricated illness, chronic fatigue syndrome, paediatrics

How can we get better at recognising cases of fabricated illness? A service improvement project within a paediatric chronic fatigue service.

Fabricated or induced illness (FII) by another is presumed to be a rare form of child maltreatment which occurs when a caregiver falsifies and/or induces a child's illness, leading to unnecessary and potentially harmful medical investigations and treatment (Bass & Halligan, 2014). Several variations of its name exist, with DSM-5 (American Psychiatric Association, 2013) introducing the condition as factitious disorder, and factitious disorder imposed on another, whilst historically it was previously known as Munchausen syndrome by proxy. As well as its' name, the definition of the condition has also been controversial (Flaherty & MacMillan, 2013).

Maltreatment occurring through fabricated illness can be a severe form of child abuse due to serious risks of physical, emotional, and educational harm to the child. There is a 25% increased risk of death due to actions related to fabrication (Kozłowska, Foley, & Savage, 2012). Fabrication is best thought of along a spectrum of presentations, rather than a single entity; including exaggeration of real disease and symptoms, misreporting signs and symptoms, fabrication or distortion of illness history, fabricating the clinical picture, and producing signs and symptoms of illness. Potential harm to a child can occur due to direct actions of the caregiver, unnecessary efforts by medical staff to diagnose and treat a non-existent condition, as well as the social, emotional and educational impact of the fabrication (Flaherty & MacMillan, 2013)

The identification and diagnosis of fabricated or induced illness in a child is a complex process that requires clear communication between health care professionals, thorough evaluation of medical history, and a team-based approach (Bass & Halligan, 2014). Guidance for the identification and management of cases has been published by the Royal College of Paediatrics and Child Health (2009), and by the Department for Children, Schools and Families (2008). However, due to the rare nature of fabricated illness and the complexity of presentations, it remains a difficult condition for clinicians to recognise and respond to appropriately. As such, this form of maltreatment can often go unrecognised, or underreported even when suspected or recognised. Such rarity and complexity is likely to mean that clinicians often do not feel confident in their ability to identify and appropriately manage such cases, with one study finding that professionals required a strong degree of certainty before reporting cases of fabricated illness (McClure, Davis, Meadow, & Sibert,

1996). A review by Sheridan (2003) concluded that only approximately one third of cases of suspected fabricated illness in a child had been reported.

Although factitious disorder is widely accepted in both ICD-10 and DSM-V, there continues to be debate about the appropriateness of the categorisation. Bass and Halligan (2014) argue that the condition is ‘conceptually flawed’ as guidance is not provided about the role of conscious or unconscious motivation and action. The authors, amongst others, cite the difficulty of the task of determining whether actions taken by parents and patients are intentional or voluntary, conscious or unconscious. It remains unclear how clinicians are supposed to infer the level of conscious awareness and intention in those who exaggerate and fabricate symptoms (Krahn, Bostwick, & Stonnington, 2008). An important question is whether a person believes themselves or their child to be ill. If this is the case then anxiety may leave them likely to embellish subjective reports of symptoms to get care they believe is needed. It is here that factitious disorder clearly begins to overlap with what are known as somatic disorders, and the lines defining these classifications are notably murky.

Chronic Fatigue Syndrome, or Myalgic Encephalomyelitis (CFS/ME) is defined by the Royal College of Psychiatrists and Child Health as “generalised fatigue persisting after routine tests and investigations have failed to identify an underlying cause” (Royal College of Paediatrics and Child Health, 2009, p. 28). It is characterised by persistent physical and mental fatigue that is not due to exertion and is not alleviated by rest. The fatigue can be debilitating, having a significant impact on daily living. Accompanying symptoms can include joint and muscular pain, headaches, stomach problems similar to irritable bowel syndrome, painful lymph nodes, dizziness and nausea, difficulties with concentration and memory, and sleep disturbance (Dennison, Stanbrook, Moss-Morris, Yardley, & Chalder, 2010). A diagnosis of CFS/ME is a diagnosis of exclusion, meaning that medical assessment and blood tests must first rule out other possible diagnoses, such as Coeliac disease and irregular thyroid functioning. If no unusual bio-medical markers are found and symptoms continue for three months, NICE guidelines (NICE, 2007) recommend that a diagnosis of CFS/ME can then be given in children. Prevalence has been estimated at between 0.1-2% of children under 18 years of age (Crawley, Hunt, & Stallard, 2009). CFS/ME has been shown to be linked to significant absenteeism from school (Crawley & Sterne, 2009), restricted social and leisure and activities, negative impact on peer and family relationships (Rangel, Rapp, Levin, & Garralda, 1999), along with withdrawal and isolation (Lloyd, Chalder, & Rimes, 2012), and therefore poses a significant threat to a young persons’ healthy development. Whilst CFS/ME is now recognised as a debilitating illness, historically it has

been marred by a lack of understanding, uncertainty and controversy (Holgate, Komaroff, Mangan, & Wessely, 2011).

As in any health condition, fabrication of illness and symptoms will occur amongst a very small proportion of those presenting with CFS/ME. This is the case across all health conditions. However, when fabrication occurs within a CFS/ME population or service, it may present particular challenges and difficulties. Because the definition of CFS/ME consists exclusively of symptoms and the exclusion of other explanations, fabrication of symptom reports is easier for conditions where diagnosis is confirmed through medical assessment and testing. This may mean that potential fabrication within a CFS/ME population can be much harder to recognise and respond to. Additionally, to further complicate the picture, it is important to hold in mind that many children who are subjected to fabricated or induced illness by another also have, or have gained, a genuine physical or psychological disorder (Bass & Halligan, 2014).

This project aimed to gather information about staff experiences of fabricated or induced illness by another within in a paediatric CFS/ME service. It hoped to understand more about the particular difficulties of recognising and managing FII within a paediatric CFS/ME setting, to gauge staff knowledge and confidence about FII, and gather information about useful practices when FII is considered. It was hoped that through consultation with staff, recommendations could be provided to further support staff if, or when, faced with cases of suspected fabricated illness. It is hoped that clients who attend the service, would therefore be able to benefit from increased staff knowledge and confidence in relation to this issue.

Method

This project was conceived with the Safeguarding Lead of a specialist Paediatric CFS/ME service. The rate of suspected cases of FII in the service was unknown, but the safeguarding lead estimated roughly ten cases of presumed FII within the service over the last two years, with approximately half of these requiring a referral to social services. Following this, the researcher met with the Clinical Lead of the service to further develop this study, as well as to consider ethical issues and concerns given the sensitive and contentious nature of FII. Whilst FII is likely to affect only a very small number of clients within the service, because of this rarity and therefore staff's likely limited clinical experience, it was felt important to understand more about staff experiences of FII.

This service improvement project was granted full ethical approval by the University of Bath Psychology Department Ethics Board.

Design

A qualitative semi-structured interview design was employed. This was chosen to allow participants to freely express their opinions and thoughts regarding FII, enabling rich and varied data to be collected.

Participants

It was identified that there were twelve clinical staff working within the service at the time of data collection (summer 2016). The service contains a broad range of clinical staff including; paediatricians, psychologists, and physiotherapists. All staff were approached in person at team meetings and via email about participating in this project. In total, eight staff members took part in interviews, and one staff member answered the semi-structured questions via email. All professions within the service were represented in these interviews.

Materials

A semi-structured interview schedule, devised in collaboration with supervisors and the clinical lead of the service, was used in each of the interviews conducted (Appendix C). Four interviews were conducted face-to-face and four were conducted via telephone. All interviews were audio recorded using a voice recorder.

Procedure

Clinical staff within the Paediatric Chronic Fatigue Service were invited to participate in interviews. Respondents were provided with full information about the study, and completed a consent form if they chose to take part (Appendices D, E and F). All interviews (face-to-face and telephone) were between ten and twenty minutes.

Analysis

Audio recordings of interviews were transcribed and anonymised. Transcripts were analysed using thematic analysis. This is a qualitative method of analysis used for “identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). The approach aims to identify patterns of meaning across a dataset through a rigorous

and recursive process. Braun and Clarke's (2006) formative article on thematic analysis outlines a series of steps, or phases, for researchers conducting thematic analysis to follow. This procedure was followed, and an inductive, or data-driven, approach was taken, focusing on semantic themes. The data set was hand-coded independently by two researchers, themes and patterns were then collaboratively generated.

Whilst guidelines and procedures for thematic analysis were followed, researchers cannot free themselves of epistemological and theoretical commitments, and as Braun and Clarke note, data is not coded in an "epistemological vacuum" (2006, p. 12). As a researcher, it was important to acknowledge my epistemological position having previously worked within the paediatric CFS/ME service, and to consider how this may have influenced my ability to be objective. The data was independently coded by two researchers, one of whom had not worked within the service. This was hoped to ensure that analysis remained inductive and data driven.

Results

From the thematic analysis two over-arching themes emerged, these were named; 'Challenges' regarding fabricated illness, particularly in the context of paediatric CFS/ME, and 'What helps' if fabricated illness is suspected. Within these two broad over-arching themes, five themes emerged, which contained several sub-themes. These can be seen in Table 2.1, and will be discussed below.

Table 2.1
Themes from thematic analysis

CHALLENGES
Relationship and communication with family
<ul style="list-style-type: none"> • Difficulties maintaining a therapeutic relationship • Withholding information from the family • Hearing the voice of the child
Misunderstandings of FII
<ul style="list-style-type: none"> • Knowledge about FII • Disentangling CFS/ME and FII
Attitudes and Understanding of CFS/ME
WHAT HELPS
Working with others
<ul style="list-style-type: none"> • Teamwork • Mentors • Liaising with other services
Practical Considerations
<ul style="list-style-type: none"> • Documentation • Guidelines

Challenges

Relationship and communication with family. This theme describes how communication and the therapeutic relationship with the family can be difficult in cases. The necessity of withholding information and the nature of difficult conversations can contribute to the challenges of maintaining a supportive and therapeutic relationship.

Difficulties maintaining a therapeutic relationship. Several participants highlighted that when working with cases where FII is suspected that there can often be difficult conversations to be had with the family, and this can make it tricky to maintain a therapeutic relationship.

“I think any situation that you’re saying to the family ‘we need to talk to social services’, is always a difficult conversation to have clinically ...I can imagine

needing to take a deep breath before having that conversation with the family about it, because it's pretty tough". Participant 3.

"I think it's maintaining a relationship, a working relationship between the young person and the family members. It's maintaining an element of trust and it's still making sure that it's the young person safety which is paramount". Participant 7.

Several participants highlighted a balance between wanting to be trusting of the family and what they are telling you, whilst also remaining curious if concerns are being raised.

"It's a delicate balance between what's really going on, and believing what they say, but also kind of being querying and questioning". Participant 5.

Also raised was that there can be difficulties in communication with families where FII is suspected. There may be inconsistencies in communication and families might seek advice and opinions from multiple sources or services.

"You face the challenge of actually saying, 'no there is a problem here that we need to address, but it's not what you think it is, instead of Chronic Fatigue it's something different.' I think that's a massive challenge and it's very confrontational and ...people don't like to not be believed". Participant 4.

Withholding information from the family. Several participants expressed concerns about knowing when to share information with a family, and when it is appropriate to withhold information.

"Understanding that you have the right to, if you have these sort of suspicions, to hold a multi-professional meeting, or to make a call to social services without telling the family. So in that way it's different to usual, when you're trying to involve the family if you make referrals to social services, but this is one case where it can be harmful to do that". Participant 2.

Others raised that withholding information from a family can feel unsettling, given the propensity for working transparently.

"It's hard sometimes because if the parents aren't aware of what you're doing. That's quite hard as well because you're having a relationship with them in the clinic, and yet you are often meeting privately to discuss things, and it does make me feel a bit uneasy sometimes". Participant 8.

Hearing the voice of the child. Some participants highlighted how information is often gathered from parents, therefore making it difficult to comprehend the child's point of view, especially from younger children.

"It's very subjective in its' nature of presentation, especially with the paediatrics, you're going a lot on parental reports and so you are very much taking on parents' words of what the child has been struggling with. Especially younger children where they do not necessarily have much of a voice". Participant 4.

"And with young children, or sometimes children where they are less well, we know that the parents do more of that; they do more of the recording and more of the feedback to us. So I suppose there is potential there for more fabrication essentially". Participant 3.

Misunderstanding of FII. This theme captures that FII is a complex issue and is not always well understood. Participants highlighted that it can be particularly difficult when considered in the context of CFS/ME.

Knowledge about FII. Interviews with participants indicated varying levels of understanding within the team about FII.

"I haven't worked with anyone with it before. I don't think I've had any specific training on it yet in my career. So I've got some understanding of what it is from discussions with the team and general awareness". Participant 3.

"My understanding is probably quite stereotypical of what it is; how it is presented on TV". Participant 5.

Most participants identified that there is a spectrum of presentations of FII, but several participants articulated that they were unsure how prevalent FII is, particularly within a CFS/ME setting.

"I don't know a lot about it and I don't know how prevalent it is, I mean I would guess it's not really prevalent but I'm maybe very naïve". Participant 6.

Disentangling CFS/ME and FII. Nearly all participants raised the difficulties and complexities of separating CFS/ME and FII.

"I think the thing with CFS/ME is that obviously it's not something that you can see, sometimes there are a few physical things that you can notice but actually generally it's one of those frustratingly unseen illnesses and so it's actually probably easier to

pretend you have something like CFS/ME or any other sort of long term sort of IBS-type, fibromyalgia, pain type of conditions". Participant 5.

Participants spoke about both conditions being diagnoses of exclusion, which rely on subjective reports, often from parents. This can blur the lines between presentations, but over time, a clearer picture can emerge.

"Because it is an illness that is diagnosed by exclusion, we're already making, not making assumptions, but we're kind of placing information on what the family share with us". Participant 3.

"I think because of the nature of Chronic Fatigue in that there is an absence and it's necessary for there to be an absence of any other medical explanation, it's very difficult for clinicians to have a really really clear cut picture of a Chronic Fatigue diagnosis". Participant 4.

Attitudes and understanding of CFS/ME. Several participants spoke about CFS/ME not being a well understood condition by both the public and some health professionals.

"If you don't understand Chronic Fatigue, people can think that they are putting it on, or ...it's just being over-tired or whatever, and have this suspicion over them from people outside". Participant 6.

Others can be dismissive of symptoms of CFS/ME and therefore families have often had to fight to get a diagnosis of CFS/ME and support.

"Families will have had to work to get here, you know, to convince GPs, to convince school; this is how they describe it to us. So I feel it has been a real battle for people to listen and take it seriously". Participant 3

Participants spoke about psycho-education often being helpful for other services and schools to help them understand more about CFS/ME. This can therefore hopefully prevent other professionals jumping to conclusions about FII.

"The other thing that we get involved with often is when we think the child probably isn't, hasn't, got fabricated illness and ...the parents are being prosecuted for attendance issues. And that sort of thing is because ...they don't understand what Chronic Fatigue is, and how it affects the child". Participant 2.

"That kind of touches more generally on the understanding of Chronic Fatigue Syndrome generally; that it isn't very well understood in some areas. Even I guess sometimes in medical professionals. I think still sometimes we hear people say that

how maybe other medics or health care professionals have maybe been dismissive with them about symptoms or about the label themselves. I think the Chronic Fatigue label. And yeah, so that bit of psycho-education around that can be really helpful”.

Participant 1.

What helps

Working with others. This theme was found across all interviewees, and encapsulates the importance of liaison and support from other professionals. The value of input and perspectives from others was emphasised, as well as the importance of shared responsibility.

Teamwork. All participants stressed the importance of case information being held by the team, rather than by a single professional. This was highlighted as important to enable case discussion with other professionals, a sharing of ideas, and to be emotionally supported by colleagues.

“I think that working within a supportive team and being able to draw on some supervision and being able to be in open communication with various different...people who are involved, it makes you feel more confident” Participant 1.

Several participants also spoke about the value of learning from other colleagues’ experience.

“It’s just sometimes you need to all get together and kind of share information to...realise that it is actually becoming a fabricated illness concern” Participant 8.

“I think developing an atmosphere of openness, so people don’t feel intimidated by...the doctors, or whoever, to approach for advice” Participant 2.

Mentors. Additional to stressing the importance of teamworking, several participants spoke about the importance of having someone with experience to discuss cases with.

“Having that wealth of experience is very containing, feel better off” Participant 4.

Several participants mentioned that clinical supervision is appropriate for this, but others also highlighted the usefulness of having one named person holding a safeguarding role, as a useful point of contact.

“I spoke to [X] who was our safeguarding lead at the time, so she was able to sort of talk through the different levels and the different processes, so that was really helpful. To have somebody named to go and discuss it” Participant 8.

“Really helpful having that one person just to say, right we will be moving forward with this” Participant 4.

Liaising with other services. Many interviewees spoke of the importance of gaining information and perspectives from other services working with the family. The value, support, and information than other agencies can offer was spoken about.

“It’s the concept of the jigsaw; that you’ve got one piece but somebody else has got another piece. And it’s not until you put it all together that it makes a picture”
Participant 2.

As well as mentioning how other agencies can be helpful, some difficulties with liaison were acknowledged.

“If school don’t feed back to us saying ‘well actually no that’s completely not true’, or if we’re not allowed to share information with school or other professionals, that can also be quite difficult as well because then sometimes you are not aware of something not adding up” Participant 8.

Practical considerations. This theme was mentioned by most participants and highlights that there are important practicalities to hold in mind when working with cases where FII is suspected. This theme can be broken down into two sub-themes.

Documentation. Several participants stressed the importance of evidencing and keeping records of all communications (and lack of contacts) with the family.

“So it’s worth saying ‘ok I’m going to take real care to write down everything that’s been said, so that I know I’ve got accurate notes’. Again that’s probably the thing...if there are any inconsistencies, that you triangulate them really; and you cross-check”
Participant 2.

“I should think, very very important to keep really accurate notes...written information has got to be hugely important, in respect of you know; timings, dates, times, people involved and everything. I think that’s one of the main difficulties, I should think.” Participant 6.

This need for detailed documentation was acknowledged by some participants to be time consuming, and they stressed it is important that the impact on one’s workload is acknowledged.

“You’re going to have to kind of delve through the history and often doing timelines or having to contact everyone, so this all takes time which is quite hard, but if you’ve got a booked out clinic, trying to find time to do that, to look into that, so that’s quite tricky.” Participant 8.

Guidelines. Most participants highlighted that it was important to know what to look out for, and what to do if you have suspicions about FII. The importance of knowing who to contact if you had concerns, and when a referral to social services might be necessary was also mentioned. It was raised by several participants that they felt that they lacked knowledge about what to do and who to contact if they were concerned about FII.

“I’d need to do some background reading about the condition and about the normal pathways which are set down for such situations. I don’t know those off the top of my head. There’s bound to be specific pathways, specific boxes that need to be ticked, but I don’t know that stuff off the top of my head so I would make sure I found that out”. Participant 7.

Several participants indicated that a set of guidelines would be helpful to ensure they felt confident knowing how to proceed.

Discussion

The interviews indicated that staff had a range of knowledge and experience working with FII, with some experienced team members, and others who had not experienced the condition clinically. Unsurprisingly confidence amongst team members in recognising and acting on suspected cases of FII was varied.

A theme focusing on challenges when working with suspected caregiver FII emerged. This involved several challenges that are likely to be relevant when working with families with FII across health conditions. Participants highlighted that the therapeutic relationship with families can be difficult, particularly when staff are required to have difficult conversations about your suspicions of FII, or need to withhold information from the family. These concerns are justified, as honesty and trustworthiness are found to positively contribute to the therapeutic alliance (Ackerman & Hilsenroth, 2003), therefore instances where information is withheld for the safety of the child are likely to impact on the relationship between the family and the professional. A challenge that was shared by several participants was a lack of knowledge and understanding about fabricated illness. This is presumably expected due to the rarity of presentations, and therefore emphasises the pivotal

role of experienced clinicians. It is acknowledged throughout the literature that there is a lack of clarity amongst professionals as to what constitutes FII (Lazenbatt, 2013), thus additionally contributing to an already complex situation.

Other challenges that arose were more specific to working within a CFS/ME service. Nearly all participants spoke about the potential difficulties of separating or disentangling CFS/ME from cases where it is fabricated. The absence of medical testing and diagnosis of exclusion for CFS/ME make this job all the harder. Several participants spoke about the lack of understanding commonly found around CFS/ME (Holgate et al., 2011). There were concerns that incorrect perceptions of the condition can lead to individuals making assumptions about fabrication. It was clear that professionals in the CFS/ME service not only have a role to be mindful of the existence of FII, but also to educate others about CFS/ME to avoid wrongful assumptions and judgements.

A second theme emerged focusing on what helps when professionals may have suspicions of FII. All participants emphasised the importance of collaborative and shared working. This was voiced as important both to aid gathering of information and to benefit from the expertise of colleagues. This is consistent with literature and guidelines, which recommend multidisciplinary consultation due to the complexity of diagnosing FII (Bass & Halligan, 2014; Department for Children, 2008; Flaherty & MacMillan, 2013; Horwath, 2003). The importance of having a named professional leading on cases was highlighted by staff, this is in line with guidance that a 'responsible paediatric consultant' should be named and take lead responsibility for management of cases where FII is suspected (Royal College of Paediatrics and Child Health, 2009). The importance of carefully documenting staff involvement with families, and having guidelines to refer to was also highlighted.

Results of this project were shared with the clinical lead of the service. Following this, the results of the project were presented at a team meeting to clinicians within the paediatric CFS/ME team (slides can be found in Appendix G). Information was provided about FII, about the research questions, the design of the study, and results found. Following this, a discussion was had with the team about improvements that could be made to help them feel more confident and better able to manage concerns about fabricated illness. As well as sharing the information and themes that had emerged from the data, a number of recommendations were made. These recommendations emerged, or were inferred, from the interviews. It was hoped that these recommendations could lead to improvements for the service by increasing staff knowledge and confidence, and therefore indirectly benefiting service users.

Recommendations

From the themes generated in the thematic analysis the following recommendations were made:

1. Staff showed varying levels of confidence and knowledge about FII. Therefore, training about FII would be beneficial. Specific areas that may be useful include the nature of FII, prevalence rates, and important signs to be alert for.

“It would be useful ... know what sort of questions to ask, to know what the prevalence is within CFS/ME generally and also within our clinical population here. Just to know if it’s something I’m just oblivious to that I should be looking out for more, or if it’s just one every ten years”. Participant 5.

“it’ll be really helpful...for fabricated illness is to have sets of guidelines of what to look out for, what potential triggers could be, to make you think that it could be fabricated illness...a checklist almost, just as a prompt and to know what you’re looking for...and guidelines of what to do, certain questions that would be helpful to ask.” Participant 5.

2. Additional to formal training, several staff members spoke of case discussion being particularly helpful. Whilst staff spoke about a current case discussion slot that could be used for this, the idea was also raised of more experienced members of the team presenting cases they had worked with involving FII.

“Training. Direct explicit training on what to do...even like role plays of practicing having those conversations with families, or examples of previous situations; like what the clinician has done, and things they have found helpful when doing that piece of work”. Participant 3.

“More knowledge and examples of it....to be given examples, specific examples of incidents. How to deal with it and who to talk to about it.” Participant 6.

“discuss them with the team...anything colleagues would perhaps do differently or in their experience what would have helped”. Participant 8.

3. Clarification and clear guidance on referral pathways and guidelines to follow should FII be suspected. This could be achieved through familiarisation with relevant guidelines regarding FII, particularly those by the Royal College of Paediatrics and Child Health and the Department for Children, Schools and

Families (Department for Children, 2008; Royal College of Paediatrics and Child Health, 2009), and liaisons with external agencies.

“Having some kind of really defined pathway would be really helpful and having some training for that would be really good”. Participant 4.

“What would benefit us is a direct pathway and link to other professional bodies that should be involved with a young person if this is suspected”. Participant 7.

“clearer referral pathways and clearer guidance”. Participant 1

4. The importance of team working, communication, and support from colleagues was highlighted by all participants. It is important that the service considers how they maintain this within an expanding service, composed of multiple satellite sites.

“The difficulty for us as a team working with far distant patients, is that if something like that comes up, if we are going to be involved, we have to be able to go to those sort of meetings...I think there are practical difficulties in running a service that goes so far afield”. Participant 2.

5. Acknowledging that these cases can be difficult to manage, and both draining on time, as well as emotionally demanding. It is therefore important that support structures are in place to ensure staff are appropriately supported.

“If someone is sort of suspected to have it, maybe just being given a little more time maybe so that you’ve got that time to do the extra things and make those phone calls”. Participant 8.

Following discussion with the team a clear action plan was made for implementation of some of these recommendations, and others that were contributed by the team. Firstly, a summary document of this project, along with the presentation slides were circulated to all members of the team. Additionally, relevant guidelines (Department for Children, 2008; Royal College of Paediatrics and Child Health, 2009) were circulated, and added to a shared Safeguarding electronic file for the team, to be used for future reading or as reference when required. The safeguarding lead for the team agreed to incorporate FII into the current safeguarding procedures, with a flow-chart of processes to be complied. The team were keen for relevant cases to be brought to case discussion slots. Additionally, several members of team reported finding the presentation useful for broadening their knowledge and conceptualization of FII.

The qualitative nature of this study did not seek to ascertain numbers of cases within the service where FII was suspected, and the specific processes through which they were managed. However, this information would have been retrospective and purely based on clinician self-report and was therefore thought not likely to be accurate, particularly when multiple professionals are likely to have been involved in a case. In order for this study to be built on, it is important that recommendations are considered by the service and implemented as necessary. It is crucial that these improvements are outcomed to ensure the usefulness of recommendations is reviewed and monitored.

In summary, this study sought to explore staff knowledge and confidence working with suspected cases of FII within a paediatric CFS/ME service. Staff identified several challenges that have been highlighted within the literature. However, additional challenges were identified that are perhaps unique to working within a CFS/ME service when considering FII. It is therefore crucial that staff are appropriately supported and confident, if and when, working clinically with clients where FII is raised as a concern.

Lay Summary of Research

Fabricated or induced illness (FII) by a caregiver is a very rare form of child abuse. It can occur in many forms; from exaggerating a child's symptoms, to actively producing symptoms of illness. It is often not well understood by both the public and professionals. This study sought to explore staff's experiences working with cases where FII is suspected, within a paediatric Chronic Fatigue service. Chronic Fatigue Syndrome is a condition that has historically not been well understood. Whilst there is increasing understanding amongst professionals about the nature of this illness, it can only be diagnosed if no other causes of symptoms can be found. This means that recognising FII could be trickier for professionals working with this population.

Staff working with a paediatric Chronic Fatigue Syndrome/Myalgic Encephalomyelitis CFS/ME service were interviewed about their experience and knowledge of FII. The interviews were analysed for themes shared by participants. Staff identified challenges that may be shared when identifying FII in other healthcare settings, but also challenges that may be unique when working in paediatric CFS/ME.

It is therefore important that staff working within this setting are supported and informed about FII, and aware of guidelines for its' management.

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Chapter 3. Main Research Project

“I feel as though it will help me feel better, but it usually just makes things worse”. The role of self-harm material on the internet.

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Abstract

Objective: This novel study sought to examine the prevalence of online self-harm activity amongst those who self-harm and how this impacts on self-harming practices and related distress. **Method:** A small innovative experimental study (N=3) sought to look at real-time effects of viewing self-harm material online. A cross-sectional study of young adults (N=126) compared differences between those who view self-harm material online and those who do not. The impact of appraisal of online content was explored in both studies. **Results:** 48% of the sample reported currently viewing self-harm material online, with an additional 23% reporting having previously viewed such material. Stronger desire to self-harm and greater psychological distress was found amongst those who view self-harm material online. Due to the small sample size in the experimental study causational inferences about the role of viewing self-harm material online cannot be made. **Conclusions:** Findings suggest that viewing self-harm material online is common amongst those who self-harm and that those who view self-harm material online may have stronger urges to self-harm and greater psychological distress than those who do not view such material online, thus indicating a higher risk group.

Keywords: self-harm, self-injury, online, internet.

Public Health Significance Statement: This study suggests that amongst young adults who self-harm, those who view self-harm material online have stronger urges to self-harm and greater psychological distress than those who do not view such material online.

“I feel as though it will help me feel better, but it usually just makes things worse.”

The role of self-harm material on the internet.

Self-harm has been recognised as a trans-diagnostic behaviour associated with psychological distress and increased suicidal risk. The rise of the internet and social media has enabled such information to be easily shared and accessed. To date, research directly examining the relationship between viewing self-harm online and levels of self-harming behaviours and psychological distress is limited. It is unclear whether viewing self-harm online exacerbates or alleviates self-harm practices. The aim of this study was to investigate this relationship, as well as whether appraisal of online content viewed may contribute to the inconsistent effects found in the literature.

Self-harm

Self-harm encompasses a wide spectrum of behaviours and can be defined as “intentional self-injury...irrespective of type of motivation or extent of suicidal intent” (Daine et al., 2013, p. 1). Self-harm encompasses a range of behaviours including skin cutting and burning, swallowing toxic substances, and hair pulling (Whitlock, Powers, & Eckenrode, 2006). Skin cutting is the most common form of self-harm, occurring in at least 70% of those who engage in self-harm practices (Briere & Gil, 1998; Herpertz, 1995; Klonsky, Oltmanns, & Turkheimer, 2003). Typically, individuals use more than one method to self-harm (Gratz, 2001; Nijman et al., 1999).

Some researchers conceptualise self-harm as part of a continuum encompassing any non-fatal act of self-harm, regardless of suicidal intention (e.g., Mitchell & Ybarra, 2007; Rodham, Hawton, & Evans, 2005), whilst others view self-harm as distinctly separate to suicidal behaviour (Muehlenkamp & Gutierrez, 2007; Walsh, 2005), with interchangeable language being used. In UK practice, the term ‘deliberate self-harm’ is commonly used to refer to all forms of self-injury regardless of intent (Kapur, Cooper, Connor, & Hawton, 2013; Singaravelu, Stewart, Adams, Simkin, & Hawton, 2015). However, the word ‘deliberate’ is often disliked by individuals who self-harm (Skegg, 2005). Thus, the term ‘self-harm’ will be used to refer to deliberate acts of non-fatal self-harm, regardless of intention.

Self-harming is most prevalent during adolescence and early adulthood (Lloyd-Richardson, Perrine, Dierker, & Kelley, 2007; Nock, 2010; Rodham & Hawton, 2009). Approximately 10% of young people aged 11-25 are estimated to engage in self-harm (Whitlock et al., 2006), with age of onset typically ranging between 14 and 24 years (Herpertz, 1995; Nixon, Cloutier, & Jansson, 2008). There are conflicting findings regarding the role of gender in self-harm practices; some research finds increased incidence amongst women (Andover, Morris, Wren, & Bruzzese, 2012; Jarvi, Jackson, Swenson, & Crawford, 2013), but a smaller body of research has suggested that gender difference may be less pronounced (Briere & Gil, 1998; Deiter, Nicholls, & Pearlman, 2000).

Self-harm behaviours occur across a range of psychiatric disorders and are not indicative of any one disorder (Nock, Joiner, Gordon, Lloyd-Richardson, & Prinstein, 2006). Comorbidities have been found with depression, anxiety disorders, emotional dysregulation, borderline personality disorder, post-traumatic stress disorder, eating disorders and histories of abuse or trauma (Andover et al., 2012; Jacobson, Muehlenkamp, Miller, & Turner, 2008; Nock, 2009; Nock et al., 2006; Sansone & Levitt, 2002; Yates, 2004; Yates, Carlson, & Egeland, 2008).

A theoretical model of the development and maintenance of self-harm has been proposed by Nock and Prinstein (2004, 2005). The model proposes that self-harm functions as both a means of regulating one's emotional experiences and as a means of communicating with, or influencing, others. Self-harm is proposed to be reinforced through four processes: intrapersonal positive and negative reinforcement, and interpersonal positive and negative reinforcement (Table 3.1). This model highlights the social and emotional functions of self-harm, drawing on social learning theory (Bandura, 1971). It suggests that self-harm may be used as a method to connect and increase affiliation with others (Hilt, Nock, Lloyd-Richardson, & Prinstein, 2008), thus potentially reinforcing such behaviours (Nock, 2009).

Table 3.1

Four-Function Model of Non-Suicidal Self-Injury (Nock & Prinstein, 2004)

Reinforcement type	Negative	Positive
Intrapersonal (emotional)	Decreases or eliminates aversive affective or cognitive state or states i.e., self-harm facilitates escape from undesired emotional states.	Increases or generates desired affective or cognitive state or states i.e., self-harm generates desired feelings
Interpersonal (social)	Decreases or eliminates aversive social event or events i.e., self-harm facilitates escape from undesired social situations	Increases or generates desired social event or events i.e., self-harm facilitates help-seeking

Self-harm and the Internet

The exponential growth of the Internet has enabled new methods for social communication and sharing of information. It is now an intrinsic part of life and the use of social media for connecting with others is commonplace for young adults (Luxton, June, & Fairall, 2012). Adolescents and young adults use the internet most frequently, predominately for social networking (Lenhart, Madden, Smith, & Macgill, 2009), and this provides a previously non-existent method for sharing and discussing subjects that were previously taboo (Westerlund & Wasserman, 2009).

The Internet has enabled communication about self-harm behaviours and online communities have developed around these practices. A growing body of research has developed investigating online self-harm practices, but prevalence data is limited. A recent study indicated that 22.5% of 21-year-olds reported suicide/self-harm related Internet use (Mars et al., 2015) and in another study 18% of school pupils who had self-harmed reported the internet and social media influenced their decision to self-harm (O'Connor, Rasmussen & Hawton, 2014). However further research is required to determine how widespread such activity is. Online self-harm activity is a constantly changing landscape, developing as the Internet and social media grows. Self-harm material is easily accessible (Singaravelu et al., 2015) and contains a range of content; from images and videos of self-harm, sharing of methods and techniques, to recovery encouragement. Whilst some studies have referred to

online content as ‘pro-self-harm’ (e.g. Boyd, Ryan, & Leavitt, 2011), often content that promotes self-harm practices is intertwined with other content encouraging recovery (Singaravelu et al., 2015), thus making it difficult to categorise as problematic or not.

Concerns have been raised about the impact of such online content. The material may potentially serve to normalise or reinforce self-harm practices, possibly at the expense of developing more adaptive strategies (Becker & Schmidt, 2005; Daine et al., 2013; Fortune & Hawton, 2005; Lewis & Baker, 2011; Whitlock et al., 2006). More recently, research has investigated the potential positive role of online self-harm activity. Self-harm is often associated with isolation and shame (Swannell et al., 2010), thus it has been suggested that the anonymity the internet can provide may enable users to make connections with others that they would not do face-to-face and thus may alleviate loneliness, provide support, and allow connection with others (Johnson, Zastawny, & Kulpa, 2010; Lewis & Baker, 2011; McKenna & Bargh, 2000; Rodham, Gavin, & Miles, 2007; Whitlock et al., 2006). However, it is unclear if these positive effects do occur.

Analysis of the content of self-harm websites has revealed that content often involves advice to encourage or conceal self-harm, as well as material labelled as potentially ‘triggering’ desires to self-harm (Becker, Mayer, Nagenborg, El-Faddagh, & Schmidt, 2004; Whitlock et al., 2006). However, qualitative information also highlights that self-harm websites can be used as sources of empathy and understanding, as communities, and as a way of coping with social and psychological distress (D. Baker & Fortune, 2008; Jones et al., 2011). A thematic analysis of the content of online posts in response to photographs of self-harm found a dichotomy in responses; individuals who reported a positive perception of photographs reported reduced feelings of loneliness and self-harm behaviours, whereas those who reported negative perceptions of the photographs reported that the material reinforced and encouraged self-harm (T. Baker & Lewis, 2013).

A systematic review by Daine and colleagues (2013) including 14 studies looked at the influence of the internet on adolescents at risk of self-harm. A mixed picture was found, with studies in support of both positive and negative influences. Whilst some studies found that the internet could provide a supportive community to aid coping, others found online self-harm activity to be associated with increased feelings of hopelessness and continued distress. The authors report that whilst several innovative and high quality studies were included, there is a need for further high quality research to understand the influence of

online self-harm material. A thematic review of 27 articles looking at the risks and benefits of self-harm material online identified four potential benefits: mitigation of social isolation; recovery encouragement; emotional self-disclosure; and curbing of self-harm practices. Three potential risks were also identified: reinforcement of self-harm; triggering self-harm urges; and stigmatisation of self-harm. This dichotomy was referred to as a 'double-edged sword' of online self-harm activities (Lewis & Seko, 2016).

Most research in this area has retrospectively analysed material posted online. Fewer studies have asked individuals directly about their online self-harm activity. Qualitative questionnaire responses from 68 individuals indicated that motivation for online self-harm activity was to seek support and to gain help and understanding. However, some participants reported stopping such online activity due to negative social interactions and triggering material (Lewis & Michal, 2016).

Current research has thus indicated a mixed picture regarding the role of the internet on self-harm practices. However, few studies have directly investigated the link between online self-harm activity and self-harming desires and behaviours. One study collecting data through telephone sampling of US youths found an association between viewing self-harm websites and thoughts about self-harm (Mitchell, Wells, Priebe, & Ybarra, 2014), with website usage indicating greater thoughts of harming themselves. A year-long longitudinal study in Australia concluded that use of online suicide discussion forums was associated with higher levels of suicidal ideation (Dunlop, More, & Romer, 2011). However, confounding variables were not well considered so causational links must be tentative. An earlier study found that 73% of 102 users of an online self-injury discussion group reported that belonging to the group had a positive effect on their self-harm, with only 11% reporting that online group participation had increased their self-harm (Murray & Fox, 2006).

In summary, current literature is inconclusive about the role of online self-harm activity; whether it may contribute to elevated levels of distress and increased self-harm, or whether it can reduce distress and self-harm. The role of additional factors that may influence this relationship is also unclear.

Current study

This study sought to examine the relationship between online self-harm activity and self-harm practices. Specifically, the research questions included: Are there differences between those who view self-harm material online, and those who do not? Does viewing self-harm material online lead to increased desire to self-harm and greater psychological distress? Does the appraisal of such online material effect whether viewing self-harm material online is helpful or harmful?

This study had two strands: First, an experimental study to investigate real-time effects of viewing self-harm material online. Secondly, a cross-sectional study (to allow for greater recruitment) sought to gather information about differences between those who do and do not view self-harm material online. Amongst those who view self-harm material online, the effects of psychological distress on desire to self-harm were investigated, and whether appraisal of online material influences this relationship. Additionally, qualitative information was gathered about motivations for viewing or not viewing self-harm material online. Each study will be described in turn below, including specific hypotheses.

Ethical Considerations

Ethical concerns were carefully considered, with the welfare of participants paramount. Such considerations shaped the design of both studies. Ethical approval was by the University of Bath Psychology Ethics Committee (Refs: 16-037, 16-210; Appendix H). Risk assessments were carried out to manage client distress and provide follow-up support if required (Appendix I). In addition, in the experimental study if participant distress seemed too high, the study did not take place. Participants gave informed consent prior to taking part in both studies (Appendix J) and full debriefing information was provided either in person or described online (Appendix K). Participants were provided signposting information to relevant services and a relaxation exercise. Care was taken to ensure test materials were fully accessible to ensure informed consent and accurate responses were obtained. Materials were piloted with two people with personal experience (PPEs).

STUDY 1: EXPERIMENTAL STUDY

As noted above, the aim of this experimental study was to investigate real-time effects of viewing self-harm material online in terms of levels of distress and motivation to self-harm. For research questions and hypotheses see Table 3.2.

Table 3.2

Study 1 Research questions and hypotheses

Research questions
<ul style="list-style-type: none">• Does viewing self-harm material online effect desire to self-harm and related psychological distress?• Does this effect depend on the viewers' appraisal of the online content viewed?
Hypotheses
<ul style="list-style-type: none">• H1: Viewing self-harm material online will impact on desire to self-harm• H2: Desire to self-harm will be impacted upon by appraisal of online material:<ul style="list-style-type: none">a. Desire will increase if material is appraised as 'unhelpful/negative'b. Desire will decrease if material is appraised as 'helpful/positive'• H3: Viewing self-harm material online will impact on psychological distress• H4: Level of psychological distress will be impacted upon by appraisal of online material:<ul style="list-style-type: none">a. distress will increase if content is appraised as 'unhelpful/negative'b. distress will decrease if content is appraised as 'helpful/positive'

Method

Recruitment Strategy

Recruitment was via local media and advertisements, and online advertising (Appendix L) for young people who would take part in the study in person. Inclusion criteria were young people (aged 17-25) who self-harmed and viewed self-harm material online. A-prior power analysis indicated 24 participants were required to detect medium effect sizes ($f=0.25$), with 80% power using repeated-measures ANOVAs, with $\alpha=.05$. However, recruitment difficulties meant this was not achieved. Four participants took part, but participation was terminated at an early stage with one participant on the clinical judgement

of the researcher. Thus, data was obtained from three participants, who were all female and aged between 19-23 years.

Design and Procedures

A repeated-measures design was used. In a university setting, participants were asked to view online self-harm material for 10-15 minutes, using the website they most frequently visit. Psychometric measures were completed before and after. Desire to self-harm was rated before, during and after exposure to the online self-harm material (Figure 3.1). The researcher remained in the room whilst participants viewed the online material. Whilst it is important to acknowledge that such a context is different to the environment where online self-harm is typically viewed, a compromise to ecological validity was deemed necessary to safeguard client welfare.

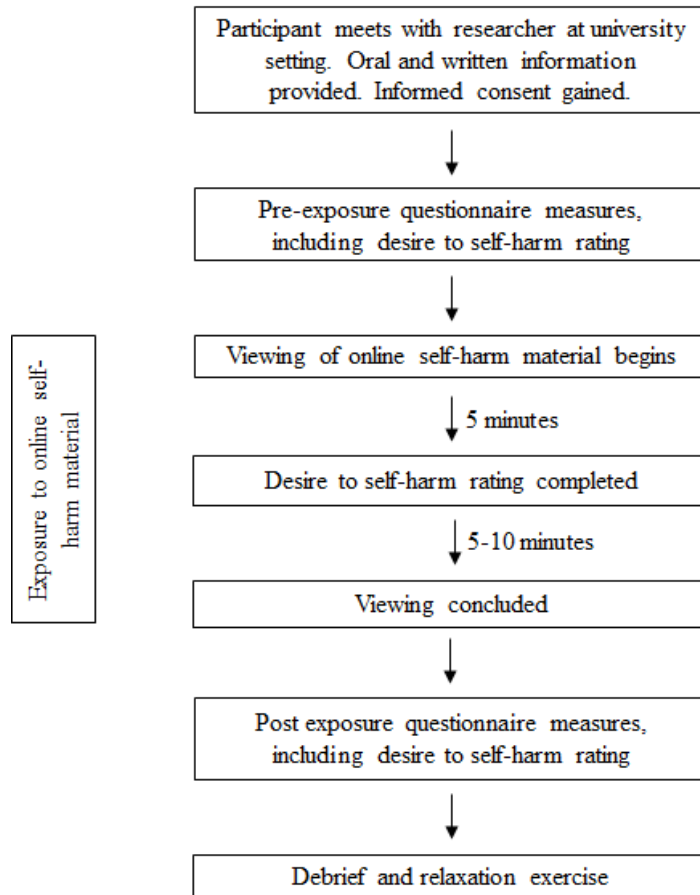


Figure 3.1. Procedure of experimental study.

Measures

Self-harm. Measuring the impact of viewing online self-harm material on actual self-harm behaviours would not have been ethical in the current context. Instead, desire to self-harm was measured to provide an indication of increased likelihood of self-harming behaviours. Participants were asked to rate their desire to self-harm on a 100-point visual analogue scale (VAS) before, during and after viewing self-harm material online (Appendix M).

Psychological distress. Psychological distress has been conceptualised as unpleasant feelings or emotions that impact on level of functioning (Ridner, 2004). The following questionnaire measures were used to assess aspects that may pertain to psychological distress and functioning. They were chosen following themes identified by Lewis and Seko (2016). Any trait measures were reworded to measure state qualities. All measures were judged to have good or excellent internal consistency (Appendix N).

Loneliness. The Revised-UCLA Loneliness Scale (Russell, 1996) is a 20-item scale for assessing loneliness. Participants are asked to rate their agreement with statements on a 1-4 Likert scale. Higher scores indicate greater loneliness.

Recovery. The Questionnaire about the Process of Recovery (QPR; Neil et al., 2009) is a 22-item measure of personal recovery. Questions focus on quality of life, wellbeing and empowerment. Participants are asked to rate items on a 5-point Likert scale, with higher scores indicating increased recovery and recovery encouragement. The measure was originally developed from service-user accounts of recovery from psychosis.

Affect. The Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988) was used to measure affect. The PANAS consists of two 10-item scales which measure positive and negative affect. Items are rated on a 5-point Likert scale. Higher scores indicate stronger affect.

Contextual information. Appraisal of online-self-harm content viewed was rated on 5-point Likert scale ranging from 1- ‘unhelpful/negative’ (e.g. “triggering”, pro-self-harm information, advice on methods of self-harm), to 5 - ‘helpful/positive’ (e.g. provides helpful information, advice to seek help, advises against self-harm; Appendix O). This scale was derived from Singaravelu and colleagues (2015), in which clinicians used a similar method to rate the content of websites.

Results

This study was interested in how viewing self-harm material online effects desire to self-harm and psychological distress, and whether appraisal of the online content viewed influences its’ impact. Due to the small sample size, results were analysed via visual inspection.

Table 3.3 shows participant ratings of the online self-harm material viewed, as rated on the 5-point Likert scale described above. Participants 1 and 2 rated the online content as ‘unhelpful/negative’. Conversely participant 3 rated the material they viewed as ‘helpful/positive’. In line with the hypotheses, it was predicted there would be changes in desire to self-harm and psychological distress following viewing self-harm material online.

It was additionally predicted that participants 1 and 2 would show increases in desire to self-harm and psychological distress after viewing the online self-harm material, whereas participant 3 would show an opposite pattern, due to their differing appraisals of the content. Similar patterns pre- and post-viewing self-harm material online were shown by the two participants who appraised the online self-harm material viewed as ‘unhelpful/negative’. A different pattern of results was shown by the participant who appraised the online material viewed as ‘helpful/positive’.

Table 3.3
Ratings of online self-harm material viewed

Participant	Participant rating of online content viewed	Classified as helpful or unhelpful
1	2	‘unhelpful/negative’
2	1	‘unhelpful/negative’
3	4	‘helpful/positive’

Note: Scale ranged from 1- ‘unhelpful/negative’ (e.g. “triggering”, pro-self-harm information, advice on methods of self-harm), to 5 - ‘helpful/positive’ (e.g. provides helpful information, advice to seek help, advises against self-harm).

Desire to self-harm increased during exposure to online self-harm material for all participants. However, when content was appraised as ‘helpful/positive’, desire to self-harm then decreased to its original level upon completion. This is in line with hypothesis one, but the effects of appraisal are unclear, and thus hypothesis two is not fully supported (Figure 3.1).

Viewing self-harm material online had an effect on loneliness for all participants. Loneliness increased after viewing self-harm online for both participants who appraised the content viewed as ‘unhelpful/negative’, whereas it decreased for the participant who appraised the content viewed as ‘helpful/positive’ (Figure 3.2). An increase in negative affect and decreases in recovery encouragement and positive affect were observed in one participant who appraised the self-harm material as ‘unhelpful/negative’. No changes were observed on these measures in the other participant with the same appraisal. An opposite pattern was found for the participant who appraised the self-harm material as

‘helpful/positive’ (Figures 3.3-3.5). These findings are in line with hypotheses three and four when considering loneliness. Support for other factors of psychological distress is less clear. However, due to the small sample size hypotheses are unable to be rejected or confirmed due to the small sample size. Results will be discussed further later in the article.

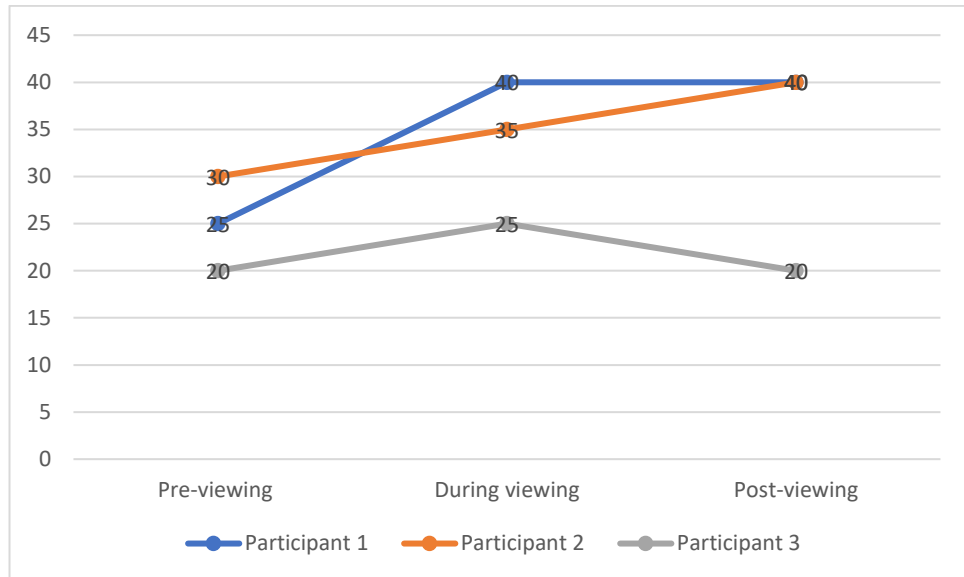


Figure 3.2. Desire to self-harm pre-, during, and post-viewing online self-harm material

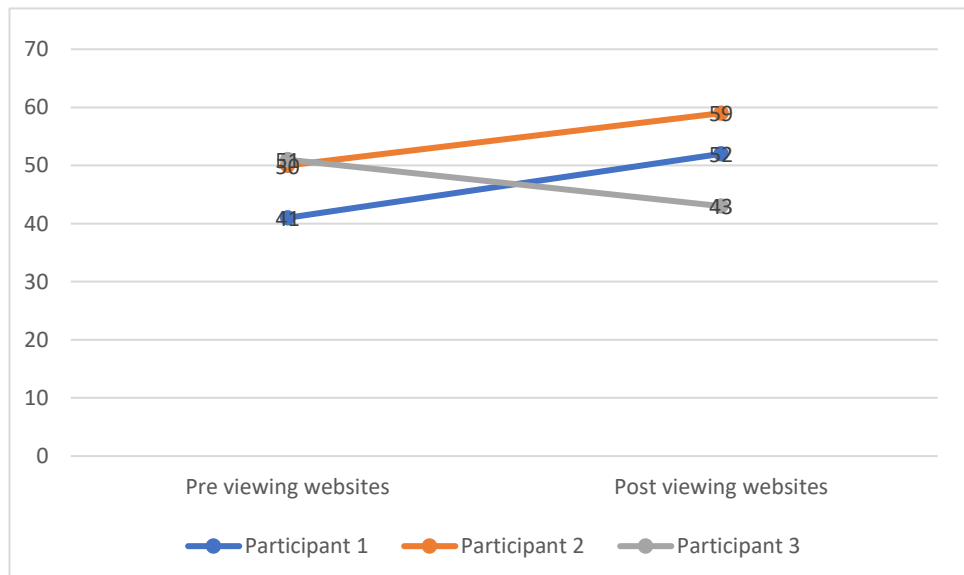


Figure 3.3. Loneliness pre- and post-viewing self-harm material online

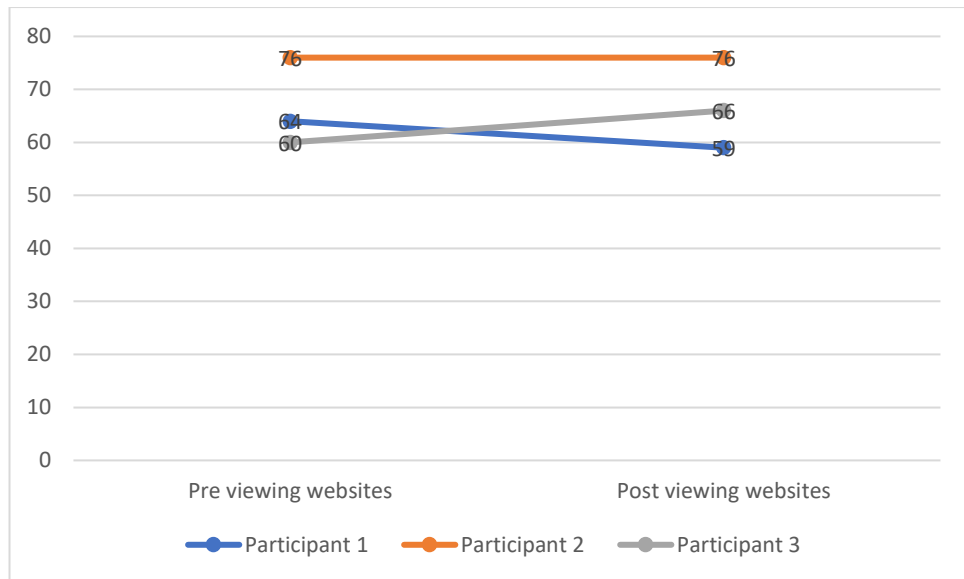


Figure 3.4. Recovery encouragement pre-and post-viewing self-harm material online

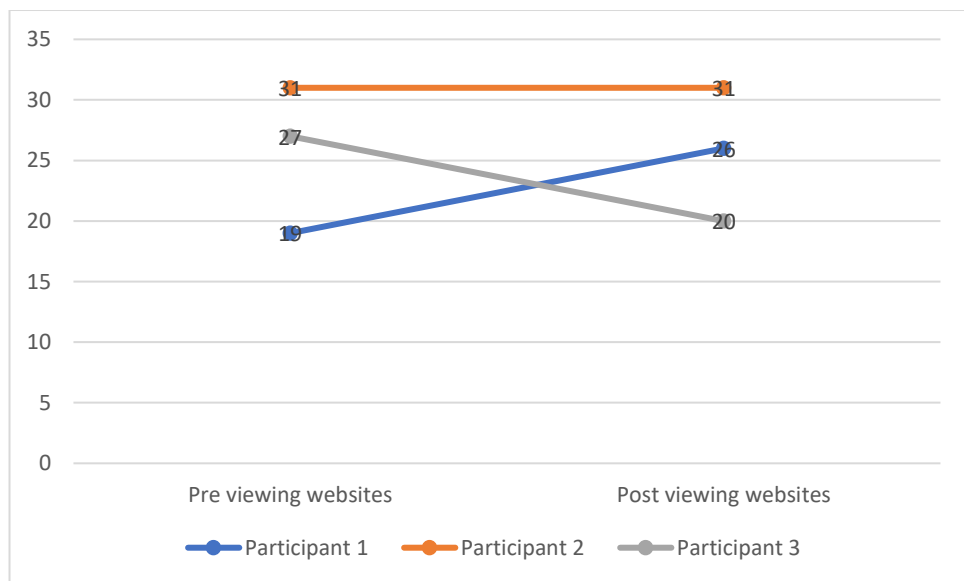


Figure 3.5. Negative affect pre-and post-viewing self-harm material online.

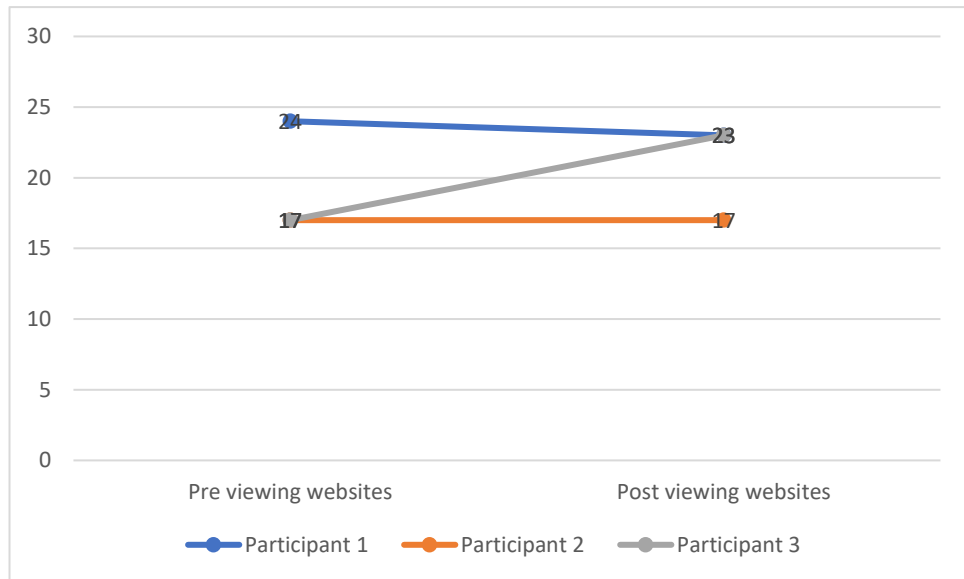


Figure 3.6. Positive affect pre- and post-viewing self-harm material online.

STUDY 2: CROSS-SECTIONAL STUDY

Research objectives

This study aimed to investigate the prevalence of viewing self-harm material online given the limited current knowledge of this, and to compare desire to self-harm and factors of psychological distress between those who do and do not view self-harm material online. Amongst those who view self-harm material online, it was investigated whether appraisal of online content influenced the relationship between psychological distress and desire to self-harm. Full research questions and hypotheses can be found in Table 3.4. Qualitative information was also collected to garner rich descriptions of motivations for choosing to view self-harm material online, or not.

Table 3.4
Study 2 Research questions and hypotheses

Research questions
<ul style="list-style-type: none"> • What proportion of individuals who self-harm view self-harm material online? • Does desire to self-harm differ between those who view self-harm material online and those who do not? • Does psychological distress differ between those who view self-harm material online and those who do not? • Amongst those who view self-harm material online, does appraisal of online content as helpful or unhelpful influence the relationship between psychological distress and desire to self-harm?
Hypotheses
<ul style="list-style-type: none"> • H5: There will be a difference in desire to self-harm between those who view self-harm material online and those who do not. • H6: There will be a difference in levels of psychological distress between those who view self-harm material online and those who do not. • H7: Amongst those who view self-harm online, measures of psychological distress will predict desire to self-harm. • H8: Amongst those who view self-harm online, appraisal of online content will mediate the relationship between factors of psychological distress and desire to self-harm.

Method

Recruitment Strategy

Participants were recruited using an Internet social media campaign, publicised via Facebook, Twitter, Instagram and Tumblr (Appendix P). In total, 129 participants were recruited but three were removed due to missing data. Therefore, participants were 126 young adults aged between 17-25 years, who identified as self-harming (for demographics, see Table 3.5).

Design and Procedure

A between-subjects design was used to compare quantitative data from those who view self-harm material online and those who do not. Prior to completing the online questionnaire participants were asked to screen themselves against the study inclusion criteria. Participants who indicated they did not fall within the required age category were removed from the study and directed to debriefing information. Participants were also removed from the study if they were not self-harming. Participation lasted approximately 20 minutes. Participants were not required to provide identifying information (apart from date of birth, to ensure age for competency to give informed consent). Online research guidelines were adhered to (British Psychological Society, 2013).

Measures

All measures in Study 1 (except for the visual analogue scale) were used in this online study (Study 2). Additional measures are listed below. All have good or excellent internal consistency (Appendix N).

Self-harm. The Alexian Brothers Urge to Self-Injure Scale (ABUSI; Washburn, Juzwin, Styer, & Aldridge, 2010) is a 5-item measure designed to assess the severity of the urge to engage in non-suicidal self-injury. Participants respond on a 7-point Likert scale, with higher scores reflecting more intense urges and desires to self-harm.

Psychological distress. Again the Revised UCLA Loneliness Scale (Russell, 1996), the Positive and Negative Affect Schedule (PANAS; Watson et al., 1988) and the Questionnaire about the Process of Recovery (QPR; Neil et al., 2009) were used. Additionally the Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001) was used to assess depressive affect. This is widely used in primary care settings as a screening measure for depression. Total scores range from 0 to 27, with higher scores indicating higher levels of depressive affect.

Contextual information. Frequency of internet use and viewing self-harm material online was collected. Type of self-harm questions were based on the Self-Harm Inventory (Sansone, Wiederman, & Sansone, 1998), which is a behaviourally based measure of self-harm. Participants were asked to rate their appraisal of the content of the online self-harm material they view, on a Likert scale as in Study 1.

Qualitative information. Open-ended questions were used to gather qualitative information about reasons for looking (or not) at self-harm material online, as well as websites viewed and search terms used (Appendix Q).

Analysis plan

Group comparisons between those who view self-harm material online and those who do not was carried out using T-tests. Correlational analysis followed by bivariate linear regression was used to compute mediational analysis of appraised of online content. (Preacher & Hayes, 2008).

A-priori and post-hoc power calculations were conducted to determine the required sample sizes to detect small, medium, and large effects (Appendix R) and indicated that this study was sufficiently powered to detect medium-sized effects. Overall, 128 participants were required (64 in each group) to detect medium effect sizes ($d=0.5$), with 80% power using between-groups t tests with $\alpha=.05$.

Content analysis was used to analyse qualitative responses (Appendix S).

Treatment of data

Three participants were removed due to multiple missing data points. No outliers were found. Assumption of normality was assessed using visual inspection of P-Plots and histograms. Measures of skewness and kurtosis were assessed, all data showed adequate normality. Homogeneity of variance was assumed following Levene's test. Assumptions for regression analyses were also checked; data was found to meet these (Appendix T).

Differences between groups were checked, and equivalent rates and methods of self-harm were found amongst participants who had never viewed self-harm online and those who no longer did, which led to these groups being collapsed (Appendix U).

Results

Description of data

The sample was almost exclusively female (92.2%) and Caucasian (91.3%), with 61.7% being British (see Appendix V for full demographics). A diagnosis of depression was most common (69.8%), with anxiety (63.6%) and Borderline Personality Disorder (45.0%) also prevalent. Cutting was the most frequent form of self-harm (95.3%). On average individuals engaged in three different methods of self-ham (see Table 3.5). In terms of viewing self-harm online, 48% of participants did so (n=60) and 52% (n=66) did not currently do so (37 of whom reported they had never viewed self-harm material online and 29 previously had but no longer did).

British participants were significantly more likely to not view and to have never viewed self-harm material online. Higher rates of self-reported depression, anxiety, PTSD, and eating disorders were found amongst those who viewed self-harm material online. Similar rates of contact with mental health services were found across groups (see Table 3.6 for descriptive statistics of questionnaire measures).

Table 3.5
Descriptive statistics

	All participants (N=126)	View online (n=60)	Do not view online (n=66)
	Mean (SD)	Mean (SD)	Mean (SD)
Sample characteristics			
Age	20.75 (2.71)	19.85 (2.65)	21.53 (2.54)
Gender	92.2% female	91.7% female	92.3% female
Nationality	61.7% British	45.8% British	75.0% British
Ethnicity	91.3% Caucasian	89.7% Caucasian	92.4% Caucasian
Contact with mental health services	65.1%	63.3%	66.7%
Mental health diagnoses			
Depression	69.8%	75.0%	66.7%
Anxiety	63.6%	71.7%	57.6%
BPD	45.0%	45.0%	45.5%
PTSD	30.2%	36.7%	24.2%
Eating disorder	20.2%	23.3%	16.7%
Bipolar disorder	12.4%	16.7%	9.1%
OCD	7.8%	6.7%	9.1%
Psychosis	6.2%	6.7%	4.5%
Types of self-harm			
Cutting	95.3%	96.7%	95.5%
Interfering with wound healing	49.6%	58.3%	40.9%
Severe scratching	47.3%	46.7%	48.5%
Burning	28.7%	31.7%	25.8%
Pinching	27.1%	33.3%	22.7%
Hair pulling	22.5%	20.0%	25.8%
Biting	20.9%	20.0%	21.2%
Swallowing dangerous substances	17.8%	15.0%	21.2%
Sticking self with needles	7.0%	10.0%	4.5%
Carving	7.0%	8.3%	6.1%
Number of methods of self-harm used	3.23 (1.56)	3.40 (1.53)	3.23 (1.54)

Table 3.6

Descriptive statistics for main measures by group and for whole sample, groups compared using t-tests

	Population mean <i>(where available)</i>	All participants (N=126)	View online (n=60)	Do not view online (n=66)	t	Sig.	Cohen's d
		Mean (SD)	Mean (SD)	Mean (SD)			
Questionnaire measures							
ABUSI*		18.09 (7.41)	20.25 (7.35)	15.89 (6.81)	3.41	.001	.620
PHQ-9*	2.30 (3.30)	17.11 (9.00)	19.37 (8.65)	15.83 (8.47)	2.32	.022	.413
PANAS NA*	16.00 (5.90)	34.31 (8.76)	36.73 (7.34)	32.25 (9.39)	2.79	.006	.532
UCLA*	36.83 (10.51)	55.94 (10.90)	59.35(10.14)	52.93 (10.73)	3.22	.002	.614
PANAS PA**	31.31 (7.65)	20.08 (8.01)	18.25 (7.13)	21.64 (8.43)	-2.28	.024	.434
QPR**		39.30 (17.49)	33.85 (16.14)	44.12 (17.37)	-3.02	.003	.614
Internet usage		4.29 (1.00)	4.37 (0.93)	4.23 (1.07)	.709	.480	.141

*Note: ABUSI = Alexian Brothers Urge to Self-Injure Scale; PHQ-9 = Patient Health Questionnaire-9; PANAS = Positive and Negative Affect Scale; PA = Positive Affect; NA = Negative Affect; UCLA = Revised-UCLA Loneliness Scale; QPR = Questionnaire about the Process of Recovery; *higher scores indicate worse functioning; ** higher scores represent better functioning; effect size=Cohen's d, where $d \geq 0.2$ = small, $d \geq 0.5$ = medium, $d \geq 0.8$ =large*

Between group comparisons

Participants who view self-harm material online reported significantly higher desire to self-harm; $t(120) = 3.41$, $p=.001$, with a moderate effect size ($d=.62$), in line with hypothesis five. Depressive affect was significantly higher for those who view online material compared to those who do not, as measured by both the PHQ-9, $t(124) = 2.32$, $p=.022$, and PANAS negative-affect scale, $t(111) = 2.79$, $p=.006$, with moderate effect sizes ($d=.413$, $d=.532$ respectively). Those who view self-harm material online were also significantly lonelier, $t(109) = 3.22$, $p=.002$, ($d=.614$). In contrast, those who do *not* view self-harm material online reported significantly greater positive affect, $t(111) = -2.28$, $p=.024$, ($d=-0.434$), and increased encouragement of recovery, $t(96) = -3.02$, $p=.003$ ($d=-.614$). These findings are in line with hypothesis six. No difference in frequency of internet usage was found between groups (Table 3.6).

Within group effects

Only negative affect, as measured by the PANAS negative affect scale, was significantly correlated with desire to self-harm, $r = .322$, $p=.021$ (Appendix W). Thus, hypothesis seven was only supported for this measure of psychological distress. When a mediating role of appraisal of online content was added, no significant effects were found (Table 3.7). Hypothesis eight was therefore not supported.

Table 3.7
Mediational analysis

	Independent variables				
	PHQ-9	PANAS NA	PANAS PA	UCLA	QPR
Direct path					
Independent → Dependent	.736 **	.396 *	-.111	.189	-.099
Indirect path					
Independent → Mediator	-.041	-.070**	.050	-.016	.016
Mediator → Dependent	.403	.858	.279	.306	.489

*Note: Dependent variable = ABSUI (desire to self-harm), Mediator = appraisal of online self-harm material; * $p \leq .05$, ** $p \leq .01$; ABUSI = Alexian Brothers Urge to Self-Injure Scale, PHQ-9 = Patient Health Questionnaire-9, PANAS = Positive and Negative Affect Scale, PA = Positive Affect, NA = Negative Affect, UCLA = Revised-UCLA Loneliness Scale, QPR = Questionnaire about the Process of Recovery*

Qualitative information

As shown in Table 3.8, the most prevalent motivation for viewing self-harm material online was to alleviate social isolation. Some participants viewed self-harm material online in attempts to prevent self-harm, whilst others used it as a method for encouraging or ‘justifying’ self-harm behaviours. Some participants reported that they view online material for both of these reasons. In contrast, those who do not view self-harm material online spoke of harmful effects of such online content, and how viewing such material can prevent recovery and prolong or increase distress. Themes are shown pictorial in Appendix X.

Table 3.8

Themes arising from content analysis

Theme	Subthemes	Description	Quotes to illustrate
<i>Why do you view self-harm online?</i>			
To feel less isolated		To feel less alone, and be able to relate to others going through similar experiences.	<i>"not wanting to be alone in my struggles"</i> <i>"to know I am not alone"</i> <i>"makes me feel less alone"</i>
Attempts to prevent self-harm	Recovery motivation To get information A release instead of self-harm To deter myself	To find a way to prevent self-harming.	<i>"inspiration and motivation"</i> <i>"to find out information and answers to questions"</i> <i>"in place of harming myself"</i> <i>"to try and control the urges"</i> <i>"puts me off self-harming"</i>
To encourage self-harm	Inspiration and an excuse To trigger	To trigger, encourage or justify self-harming.	<i>"to find new ways to self-harm and hide self-harm"</i> <i>"looking creates a stronger urge to self-harm, it gives you an excuse"</i> <i>"it's quite triggering, but that's just what I'm looking for sometimes"</i>
Double edged sword		Reasons for use can vary. Sometimes viewing can help prevent self-harm but other times it can exacerbate urges.	<i>"I feel as though it will help me feel better, but usually it makes things worse"</i> <i>"sometimes it helps me to not do it [self-harm], but usually it just makes things worse"</i>
Comparison and compulsion	Compulsion		<i>"I would get kind of hooked"</i> <i>"it was a craving"</i>

	Curiosity and comparison	To compare self-harm practices, often feeling compelled to view the material.	<i>"I just wanted to compare what I did to others" "to see if my scars are better or worse than other people's"</i>
Lack of understanding	"Don't know why"	Reasons for viewing can be hard to explain and understand.	<i>"I can't explain why because I don't know"</i>
	Self-understanding		<i>"to find out more about myself"</i>
<i>Why do you not view self-harm online?</i>			
Use is harmful		Viewing self-harm material online can trigger and encourage self-harm.	<i>"because I find that it can be triggering and sometimes encourages self-harm" "I found looking at picture made my urges worse" "they don't help, and won't make me happier in the long run"</i>
Prevents recovery		Viewing self-harm material can interfere with recovery.	<i>"the content found could sometimes be triggering and therefore avoiding it is a safer option for my recovery"</i>
Self-harm is private		Self-harm is viewed as a private act, which is not to be shared with others on the internet.	<i>"self-harm is very personal and private to me" "I don't want to see other people hurting themselves"</i>
Find it upsetting		Viewing self-harm material can be distressing.	<i>"I find it upsetting" "I don't want to see self-harm photos because it affects me physically and mentally"</i>
To avoid comparison		Viewing self-harm material online causes negative social comparisons.	<i>"makes me feel like I'm not even good at hurting myself"</i>

Discussion

The two studies sought to examine the relationship between online self-harm activity, self-harm practices and related distress. A small-scale experimental study sought to investigate whether viewing self-harm affects desire to self-harm and psychological distress, and if this is affected by appraisal of the content viewed. A cross-sectional study considered the prevalence of online self-harm activity and examined differences in desire to self-harm and measures of psychological distress between those who view self-harm material online, and those who do not.

This is one of only a small handful of studies to consider the prevalence of online self-harm activity. This study found that 48% of the sample viewed self-harm material online, and an additional 23% reported previously viewing such material. This figure is higher than other published prevalence studies (Mars et al., 2015), although sampling differences may have contributed to such differences. Further larger scale research will be needed to corroborate prevalence rates.

Significant differences in desire to self-harm and measures of psychological distress were found between those who view self-harm material online, and those who do not. Those who view such material online had a greater desire to self-harm, higher depressive affect, increased feelings of loneliness, and reduced levels of positive affect and encouragement for recovery, thus suggesting that those who view self-harm material online are a more risky and distressed group. This supports other findings, where use of an online self-harm forum was found to be significantly associated with increased hopelessness and suicidal ideation (Dunlop et al., 2011), and those who viewed self-harm online were found to feel less hopeful about recovery (Lewis, Heath, Sornberger, & Arbuthnott, 2012; Lewis, Heath, St Denis, & Noble, 2011). A recent study of self-harm presenters to A&E found that self-harm related internet use was associated with higher suicidal intent in both children and adults; thus supporting the findings of the current study; indicating increased risk amongst persons who view self-harm material online (Padmanathan et al., 2016).

However, possible causal effects of viewing self-harm material online are unclear. Are individuals who are more distressed more likely to access self-harm material online? Or, does viewing self-harm online exacerbate distress and desires to self-harm? The experimental study sought to preliminarily investigate this but recruitment proved very difficult. Whilst the sample size prevents conclusions from being drawn and hypotheses

cannot be rejected or confirmed, the tentative findings suggest that desire to self-harm may increase during viewing of online self-harm material. The impact on psychological distress is unclear. However, this is sufficient to indicate that a larger experimental study would be beneficial.

The role of appraisal of online self-harm material was not substantiated in either study and its' effects are unclear, thus suggesting that viewing self-harm material online is related to desire to self-harm, regardless of how the content of appraised. However, the small sample from the experimental study again means that more research is needed to test this further. The dichotomy found in the qualitative responses may partially explain the unclear role of appraisal. Participants reported that online self-harm material can be appraised as both helpful and unhelpful, even by the same person, reinforcing the view that self-harm material online can both trigger and discourage self-harm behaviour, depending on stage of recovery (T. Baker & Lewis, 2013) and may be a 'double-edged sword' (Lewis & Seko, 2016), as noted in the title of this paper. Very few participants appraised the online material they viewed as 'helpful/positive', with most rating the content as 'unhelpful/negative'. This bias is perhaps representative of the online content available, and may have contributed to the lack of significant findings. Qualitative responses suggest viewing self-harm material online can be both a way to prevent self-harm but also a method to 'trigger' or 'justify' self-harming, in line with conflicting motivations found by Murray and Fox (2006). This information can therefore help explain why young people choose to view self-harm material online, despite perceiving it as negative and/or unhelpful.

The qualitative responses suggest that there can be both emotional and social motivations for viewing self-harm material online (Adams, Rodham, & Gavin, 2005; T. Baker & Lewis, 2013; Johnson et al., 2010; Lewis et al., 2012; Whitlock et al., 2006) as attempts to reduce isolation, seek social support and both induce or remove emotional experiences. This indicates that viewing self-harm online may potentially serve similar functions as off-line self-harm behaviours, as described in Nock and Prinstein's model (2004, 2005). However, the quantitative findings suggest that those who view material online continue to have adverse emotional experiences, significant feelings of loneliness and strong desires to self-harm after they finish viewing. Whilst young people may access such online material as an attempt to reduce isolation, levels of loneliness continue to be higher amongst those who view this material online, compared to those who do not, thus indicating that viewing self-harm material online does not meet the need for which young people are

accessing it. Whilst this study did not directly test hypotheses in line with Nock and Prinstein's model of self-harm, future studies could test whether online-self-harm activity serves similar intra- and inter-personal functions, and therefore whether this model could be expanded to encompass online self-harm activity.

Limitations

The results of this study should be interpreted in the context of several limitations. Firstly, the recruitment difficulties and resultant very small sample size of the experimental study prevents conclusions from being drawn. Secondly, the online recruitment and data collection strategy for the cross-sectional study has implications for the generalisability of results. The use of anonymous online questionnaires required participants to provide accurate self-report information, which could not be validated independently. Possible selection bias may be evident when examining the demographic characteristics of the participants, most of whom were Caucasian, female and from developed countries. Findings may not be applicable to those outside of these domains. The online recruitment strategy may have led to a skewed sample in favour of those who use the internet to view self-harm material, more studies are required to corroborate prevalence rates. Desire to self-harm was measured as a proxy for self-harming behaviours. It is unclear whether desire to self-harm is indicative of self-harming acts and behaviours. The cross-sectional design of study two prevents causal inferences from being drawn. Whilst the small size of the experimental study means it is unable to answer causal questions, it provides a template for future larger scale studies. Future studies should seek to overcome recruitment difficulties and navigate ethical considerations to investigate possible causal effects of viewing self-harm material online on self-harming behaviours and distress.

Clinical implications

It is important that clinicians working with adolescents and young adults are aware of the role the internet is likely to play in their lives, and its potential positive and negative influences. This research suggests that viewing self-harm material online is prevalent amongst those who self-harm and is a risk factor or indicator for increased distress and risk. It is therefore crucial that clinical assessment should ask about the nature, impact, and

motivations for internet use and self-harm practices. Further research into viewing self-harm online is warranted due to the potential risks and benefits (Lewis & Seko, 2016; Rodham, Gavin, Lewis, Bandalli, & St. Denis, 2016; Whitlock, Lader, & Conterio, 2007). This information can then inform risk management plans and clinical interventions.

Conclusions

This research found that viewing self-harm material online is prevalent amongst young adults who self-harm. Increased desire to self-harm and greater psychological distress were found amongst those who view self-harm material online, when compared to those who do not. A small-scale experimental study sought to explore possible causational effects of viewing self-harm material online and whether appraisal of online content viewed affected whether viewing self-harm material online was helpful or harmful. Future research is needed to explore possible causational effects. Clinically these findings suggest that those who view self-harm material online may have stronger urges to self-harm and greater psychological distress than those who do not view such material online, thus indicating a riskier group perhaps in greater need of intervention.

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Chapter 4. Executive Summary

Hannah Rapley

Word count: 1,092

“I feel as though it will help me feel better, but it usually just makes things worse”. The role of self-harm material on the internet.

Executive Summary

Background

Self-harm occurs across mental health conditions and is associated with psychological distress and increased suicidal risk. Self-harming is most prevalent during adolescence and early adulthood, with approximately 10% of young people aged 11-25 estimated to engage in self-harm. Social media now allows for self-harm material to be shared and viewed in ways that were not previously possible. It is currently unclear how prevalent viewing self-harm material online is amongst those who self-harm and what the effects of viewing such material online are.

Self-harm material is easily accessible online and content can range from images and videos of self-harm, sharing of methods and techniques, to recovery encouragement and motivation. Whilst sometimes the content is referred to a ‘pro-self-harm’, often content that promotes self-harm practices is intertwined with other content that encourages recovery, thus making it difficult to categorise as problematic or not.

Concerns have been raised about the impact of viewing such online content; that it may normalise, reinforce and encourage self-harm, perhaps preventing the development of more helpful coping strategies. However, it has also been suggested that the anonymity of the internet can enable connection with others and reduce shame and loneliness amongst those who self-harm. The literature is currently unclear on the potential effects of online self-harm activity, with few studies looking directly at its’ possible causal effects.

Aims

This research examined how prevalent online self-harm activity is amongst young people who self-harm and how viewing self-harm material online impacts on self-harming practices and psychological distress.

Two studies were conducted to investigate these questions: Study 1 was an innovative experimental study to investigate whether viewing self-harm material online

increases desire to self-harm and psychological distress. Study 2 was the first study (to our knowledge) to look at what proportion of individuals who self-harm also view self-harm material online, and whether desire to self-harm and psychological distress differ between those who view self-harm online and those who do not. Both studies considered whether perception of the online content (appraised as helpful or unhelpful) affects the impact of viewing such material online.

Methods

Ethical concerns were carefully considered and ethical approval was obtained from the University of Bath Psychology Ethics Committee. Welfare of participants was paramount, and PPE involvement helped pilot measures.

Two studies were conducted: Study 1 was a small experimental study which sought to examine the real-time effects of viewing online self-harm material. Study 2 was cross-sectional and sought to gather a greater number of participants to look at prevalence rates and differences between those who do and do not view self-harm material online.

Study 1: Participants were recruited via local and online advertisements asking for young people (17-25 years old) who self-harmed and viewed self-harm material online. Participants met with the researcher at a university setting and were asked to spend 10-15 minutes viewing the website related to self-harm they most regularly use. They completed questionnaires before, during and after viewing. It was hoped to recruit 24 participants (as indicated by power analysis), but only three were successfully recruited.

Study 2: Participants were recruited via an online social media campaign. In total, 126 young adults (aged 17-25) who self-harm completed an online questionnaire asking about their self-harm behaviours, whether they view self-harm material online, and measures of psychological distress, including loneliness, depression and belief in recovery.

Results

Trends from the experimental study (study 1) suggest that desire to self-harm increases whilst viewing self-harm material online. However, whilst it remained raised when

the content is perceived as unhelpful or negative, if the content is perceived as helpful and more positive desire to self-harm returned to baseline once viewing is completed. It is unclear from this small sample what effects viewing self-harm material online may have on factors of psychological distress.

In the cross-sectional study (study 2) 48% of the sample reported that they currently view self-harm material online, with an additional 23% reporting having previously viewed such material. Clinically high levels of depression were found amongst participants. Participants were almost exclusively female, Caucasian and from developed countries (61% British), it is therefore important to note the limitations of generalising the results from this research.

Those who view self-harm material online reported significantly stronger desire to self-harm than those who did not view such material online. They also had greater psychological distress; being found to be significantly lonelier, lower in mood, and felt less encouragement of recovery. Whether a person appraises the online material they view as helpful or unhelpful was not found to impact on their desire to self-harm or psychological distress.

Qualitative responses collected from participants indicated that most young people view self-harm material online in attempts to feel less isolated. Interestingly participants reported that they can view such material online for contrasting reasons; as both attempts to prevent and encourage self-harm, thus supporting a previous statement in the literature that online self-harm activity is a ‘double-edged sword’, as noted in the title of this research.

This research must be considered in the context of its limitations: Firstly, the small sample size from study 1 prevents conclusions from being drawn. Secondly, desire to self-harm was measured as a proxy for self-harming behaviours. From this research, it is unclear whether increases in desire to self-harm translate into increased self-harming behaviours.

Conclusions

This research is one of the first studies to consider the prevalence of online self-harm activity and employed an innovative design to begin investigating possible causational

effects of viewing self-harm online. Findings indicate that viewing self-harm material online is common amongst young adults who self-harm and that those who view self-harm material online may have stronger urges to self-harm and greater psychological distress than those who do not view such material online, thus indicating a higher risk group. Future studies will need to determine whether individuals who are more distressed more likely to access self-harm material online, or whether viewing self-harm material online exacerbates distress and increases desire to self-harm.

Due to the small number of participants in the experimental study (study 1) currently conclusions cannot be drawn about the causational effects of viewing self-harm material online. However, this study provides a template for future research to navigate recruitment and ethical considerations.

This study has important clinical implications for those working with young people who are at risk of self-harm. Firstly, findings from this research suggest that viewing self-harm material online is prevalent amongst those who self-harm and is a risk factor or indicator for increased distress and risk. It is therefore important that clinicians ask about internet use and self-harm to inform risk management plans and clinical interventions.

Chapter 5. Connecting Narrative

Hannah Rapley

Word count: 2,333

Connecting Narrative

Development of research questions

The journey to choosing research projects was a long one, and probably the most challenging stage of the process for me. I found it difficult to develop research questions because I felt inexperienced and ill at ease with the literature base. I sought to fully immerse myself in the literature, which was time consuming and led to multiple ideas and iterations. In the future I look forward to conducting research in an area of clinical specialism where I hope to feel more familiar with the evidence base and thus hope to be driven by questions that arise from my clinical practice.

Critical review of the literature. A supervisor once told me, in an attempt at reassurance, that “even if you don’t know an ounce of CBT, just by sitting in a room with someone and developing a therapeutic relationship, you will be delivering a positive intervention”. Whilst hopefully I have now developed at least an ounce of CBT knowledge, this prompted me to think about the role of process variables in therapy and the degree of influence they may hold. As a trainee psychologist, I myself was subject to frequent assessments of my adherence and competence, and thus I found the topic of my review to be a satisfying bridge between theory and clinical practice as I sought to integrate these two skills.

Service Improvement Project. Having experienced post-viral fatigue in the past, and knowing first-hand the psychological impact of this, this topic caught my interest at the research conference in my first year. I was interested in the psychological factors related to CFS/ME, and how the condition is perceived by the public, staff and patients themselves. I was able to work with both the service lead and safeguarding lead to refine the research question and design for this project.

Whilst working on the project I also worked with the Paediatric CFS/ME team. During my placement concerns were raised about a young person I was working with regarding potential fabrication of illness by their parent. This experience put the research topic into sharp clinical focus, and enabled me to appreciate the complex range of behaviours that could fall under concerns about illness fabrication. I was able to gain first-hand

experience of how concerns were managed within the team, and the necessary steps and procedures needing to be followed.

Main Research Project. My initial interest in this area arose from my interest in acute mental health and previous experience working in inpatient units. The initial seeds of an idea for this project arose whilst working as a support worker at an adolescent inpatient unit. Lots of the young people engaged in self-harm, and often my role involved supporting them with this and helping them resist acting on urges. A lovely benefit of this role was the amount of time I was able to spend with the young people. One topic of conversation we would often discuss was the use and role of social media in young peoples' lives, particularly in relation to self-harm, and the challenges it can throw up. I remember being struck by the different reasons the young people said they viewed self-harm material online. It was from here that I sought to design a study to explore this further.

Liaison with my field supervisor was particularly helpful during the initial stages of project development. Her clinical experience working with young people who self-harm, as well as my internal supervisor's experience of research, was of huge benefit in ensuring the study was rigorous and ethically sound.

Case studies. Researching and writing the case studies has been one of my favourite parts of the training process. I have found it a useful way to document theory-practice links and ensuring that interventions were carefully considered. I found them helpful for ensuring that I was rigorous with my use of outcome measures, and integrated the use of these to complement interventions. I found myself using outcome measures more stringently in some placements than in others, and on reflection I think the ethos of placements influenced this. I am therefore mindful of how I can continue to use outcome measures sensitively to contribute to interventions, and help other team members to see the benefits of using them. By thoroughly researching the topics of case studies, I have been able to feel more confident with a wide literature base and the evidence base for several different approaches and interventions.

Service user consultation

On reflection, service user involvement is an area I would have liked to integrate into my work more fully. Perhaps working alongside service users whilst conceptualising my research could have helped me overcome my initial difficulty with developing research ideas. My interests prior to training, and informal conversations with service users shaped my initial interest in the area of self-harm. Some of the most helpful feedback I received was when piloting measures, or meeting with participants for my first study. I was sad to change the design of my main research project to an online study, as this meant I was unable to meet participants and was likely unable to gain as rich detail about their experiences. Service user involvement is an area that both the course and the NHS are keen to expand. Broadening the links between service user groups and university research courses is an area I would be interested in being involved with.

Ethical considerations

Main research project. Ethical considerations were of paramount importance whilst designing this research, and shaped the design of the study. Central to the project design was ensuring the study was ethically sound, and that participants were appropriately safeguarded. Particular concern was taken to ensure participants were not exposed to any new potentially harmful online content and that participants were appropriately supported after taking part in the research. Significant discussion was had with both supervisors considering both their clinical and research experience to design a study in which risks were appropriately managed.

As the majority of research on self-harm has been conducted with clinical samples, this project was aimed at recruiting a non-clinical population. The literature cites that the majority of self-harm is often not reported to services, thus a clinical population may only reveal a very small subset of those who self-harm. The decision to gather a population-based sample meant that ethical approval was gained through the university psychology ethics board, and recruitment was not through an NHS service. Whilst this meant the ethical approval process was less time-consuming, it also meant that there was no pool of participants available for me to contact once ethical approval had been granted.

Having to change my study design due to recruitment difficulties led to a new set of ethical considerations. By transferring the research to an online study, we were unable to provide such stringent safeguards of the participants. Therefore, the design of the study and thus the research questions had to change to ensure risks were best managed.

Service Improvement project. I was initially cautious about approaching the topic of fabricated illness, due to its contentious and potentially stigmatizing nature. I was mindful about approaching the topic in a sensitive way, and ensuring it was thoughtfully considered. The service lead was supportive of the project and helped me consider how to best approach this topic and the possible implications from it.

Data collection

Service Improvement Project. I was fortunate to have worked with the team I was conducting interviews with and therefore was able to disseminate information at team meetings and informally. The team are very research active and were interested in the project, with most staff members taking part. I enjoyed the process of thematic analysis, particularly working with another researcher to refine themes and subthemes.

Main Research Project. I was anticipating that it may be difficult to recruit for this project, as self-harm is strongly associated with feelings of shame, and thus is often a secretive activity. Additionally, those who turn to online forums often favour anonymity, thus potentially compounding recruitment difficulties. However, I did not anticipate how difficult it would be to recruit participants for the face-to-face experimental study. Due to the ethical considerations of the study, we decided that it should be carried out within a university setting, so that risks could be managed and safety plans could be followed if required. However, this therefore limited the geographical area I was able to recruit from. Despite wide ranging attempts to recruit participants; including online advertising, publishing thoroughly around universities, local colleges and youth facilitates, and use of local media, the required sample was unable to be recruited. This was incredibly disappointing, but perhaps an eye-opener into the practical challenges of clinical research. Therefore reluctantly, with an impending time scale, the design of the project had to be

altered to that of a cross-sectional study in an attempt to recruit more participants. Whilst initially we considered transferring a similarly designed study online, we were not content that we could appropriately manage and safeguard participant welfare using this medium. Thus, the design and research questions had to change.

It is important that future research considers how to overcome recruitment difficulties in this area so that causational questions can begin to be answered. Whilst the sample size meant that conclusions from the experimental study cannot be drawn, I hope that it can provide a template for future studies to investigate the effects of viewing self-harm material online.

Outcomes of research

Literature review. The process of carrying out a systematic literature review has made me increasingly mindful of my appraisals of research in clinical practice. It has helped me to pay closer attention to the methodology of studies and appraise the qualities of studies. Not feeling confident about knowing the literature base has been a stumbling block across my research projects; whether it was reading extensively prior to starting case studies, or changing research ideas due to uncertainty. Conducting the literature review has perhaps been of most benefit to this. By helping me refine my literature searching and appraising practices, I now feel more confident assessing and critiquing the quality of research studies.

This project has had direct application for my clinical practice when using CBT with children and young people. It drew my attention to process variables and factors that may be at play within the therapy room, such as adherence, competence and therapeutic alliance. As an unconfident trainee, I found it reassuring that a strong therapeutic alliance can be hugely beneficial, even if at times I may have found myself floundering with CBT principles and adherence.

Service Improvement Project. Innate in any service improvement is highlighting strengths and areas for improvement in a service's functioning. I was therefore mindful about sensitively feeding back the findings of the project to the team and ensuring that recommendations were taken on board and integrated into clinical practice. The team were very welcoming and interested in the outcomes of the study, and it led to lots of thoughtful

discussion and resulting plans. Such feedback left me feeling encouraged about the use and utility of the project. Carrying out this service improvement project, as well as my consultancy project, has encouraged me to implement other small scale improvement projects in clinical practice (e.g. reviewing two therapeutic groups). I view this as an important role for a psychologist and hope to continue this in future roles.

Reflecting on this project, it also emphasised to me another central skill that psychologists can bring to multi-disciplinary teams. Through learning more about fabricated illness, the central role of formulating a client's presentation was highlighted. Such a process can increase others' understanding and help avoid labelling and negative judgments being made.

Main Research Project. When writing up this project, it felt frustrating and disappointing not to have viable results to report from the experimental study, particularly having met with the participants who did take part who were generous with their time, open when talking about their experiences, and positive about the project and the potential findings it could have. However, reflecting on the project as a whole I feel that it has been able to offer advances and novel contributions to the research base, and hopefully can lead to future studies beginning to explore possible causation effects.

Whilst my study predominantly involved quantitative data, I thought it was important also to gather qualitative responses to illustrate and further support findings. I felt that the impact of these qualitative responses was perhaps curbed by the word limit, and I would perhaps seek to publish multiple papers from this study, to allow for richer discussion of the qualitative data.

Conclusions and plans for future involvement in research

Despite some of the challenges, the research process during this course has been stimulating and I have enjoyed developing my research knowledge and skills. The process has highlighted for me the importance of preparatory work. By identifying clear research questions which are grounded in the literature and developing a rigorously designed study the resulting research process will be much smoother and more enjoyable.

The process has also highlighted to me the importance of collaborative work when conducting research. The sharing of ideas and questions being asked of your thought process can enable reflection and clarity on the research process. At times I found the process of research to be an isolating one. In the future I would enjoy working within a research group or collaboratively with colleagues.

I look forward to working as a scientist practitioner and being both guided by the evidence base and also hopefully contributing to it. I am aware that there are challenges in making time for this within a busy NHS post, but I hope the skills I have gained can give me increased confidence to appraise, design, implement and evaluate research in my future career. The research I have conducted has complimented my clinical experiences working with children and young people. This is an area that I hope to continue working in, and applying the knowledge I have developed in.

Appendix A. Journal of Consulting and Clinical Psychology. Author Guidelines

Journal of Consulting and Clinical Psychology: Author Guidelines

The *Journal of Consulting and Clinical Psychology* publishes original contributions on the following topics:

- The development, validity and use of techniques of diagnosis and treatment of disordered behaviour
- Studies of variety of population that have clinical interest, including but not limited to medical patients, ethnic minorities, persons with serious mental illness, and community samples
- Studies that have a cross-cultural or demographic focus and are of interest for treating behaviour disorders
- Studies of personality and of its assessment and development where these have a clear bearing on problems of clinical dysfunction and treatment
- Studies of gender, ethnicity, or sexual orientation that have a clear bearing on diagnosis, assessment and treatment
- Studies of psychosocial aspects of health behaviours
- Studies that focus on populations that fall anywhere within the lifespan are considered
- JCCP welcomes submissions on treatment and prevention in all areas of clinical and clinical-health psychology and especially on topics that appeal to a broad clinical-scientist and practitioner audience
- JCCP encourages the submission of theory-based interventions, studies that investigate mechanisms of change, and studies of the effectiveness of treatments in real-world settings.

Length and Style of Manuscripts: Full-length manuscripts should not exceed 35 pages total (including cover page, abstract, text, references, tables and figures). Text should be a standard font (e.g. Times New Roman) of 12 points. The entire paper (text, references, tables etc.) must be double spaced.

Instructions on preparing tables, figures, references, metrics, and abstracts appear in the *Publication Manual of the American Psychological Association* (6th edition).

Participants: Description and Informed Consent

The Method section of each empirical report must contain a detailed description of the study participants, including (but not limited to): age, gender, ethnicity, clinical diagnoses and comorbidities, and any other relevant demographics. In the Discussion section of the manuscript, authors should discuss the diversity of their study samples and the generalizability of their findings. The Method section must also include a statement describing how informed consent was obtained from the participants and indicate that the study was conducted in compliance with an appropriate Internal Review Board.

Measures: The Method section of empirical reports must contain a sufficiently detailed description of the measures used so that the reader understands the item content, scoring procedures, and total scores or subscale. Evidence of reliability and validity with similar populations should be provided.

Discussion of Clinical Implications: Articles must include a discussion of the clinical implications of the study findings or analytic review. The Discussion section should contain a clear statement of the extent of clinical application of the current assessment, prevention, or treatment methods. The extent of application to clinical practice may range from suggestions that the data are too preliminary to support widespread dissemination to descriptions of existing manuals available from the authors or achieved materials that would allow full implementation at present.

Appendix B. Archives of Disease in Childhood. Author Guidelines

Editorial policy.

ADC includes

- Original research reports
- Short shorts and scientific letters
- Commentaries
- Reviews of clinical and policy issues
- Clinical problem solving
- International health
- Patients' experience with the healthcare system

Original reports:

These should report original research (max 2500 words, excluding abstract, table and figures and reference). The body of the report should be double spaced. The tables should be single spaced and the tables and figures should be at the end of the submission after the references. Please note that all RCT must be appropriately registered and this should be noted on the cover page.

- Word count: up to 2500 (excluding title page, abstract, tables, figures and references.
- Structured abstract: up to 250
- Tables/Illustrations: up to 5
- References up to 40

Short reports/Case reports:

Short reports are brief reports of original research and case reports are any report/case history of four cases of less.

Appendix C. Semi-structured interview script

1. What is your understanding about fabricated or induced illness?
Prompt: How could it relate d to child protection?
Prompt: Does it have any relevance to your current work?
2. Have you been involved in any cases where a clinician thought FII might be playing a role?
Prompt: What worked well?
Prompt: What was difficult?
Prompt: Did you draw on any guidelines or support?
3. What might be the particular difficulties of working with cases of suspected FII within the context of paediatric CFS/ME?
4. How confident would you feel working with cases of suspected FII?
5. What would help you feel more confident if/when working with suspected cases of FII?
Prompt: How could the team be better supported for managing suspected cases of FII?

Appendix D. Information Sheet

Appendix B and C: Participant Information and Consent forms.



Information Sheet

Improving management of fabricated or induced illness in a paediatric chronic fatigue service: a service improvement project

You are invited to take part in a service improvement project. The following information sheet gives details about the overall project and explains what will be involved if you choose to participate. Please read this sheet carefully before deciding whether you would like to take part. If you have any questions, please contact the project coordinator, Hannah Rapley, at h.rapley@bath.ac.uk.

What is the purpose of this study?

This service improvement project seeks to understand current practices regarding fabricated or induced illness within your service, and aims to improve the management of these cases. The study involves asking staff about current knowledge of fabricated or induced illnesses (FII), experience working with these cases, and how cases are currently managed and best supported.

What will be asked of me if I take part?

You will be invited to attend a brief individual interview where you will be asked about:

- Your understanding of fabricated or induce illness (FII).
- Your understanding of current practice in the service regarding FII.
- Your confidence working with cases of suspected FII.
- Your experience of working with cases of suspected FII.
- Your concerns working with cases of suspected FII.

This meeting will be audio/video recorded. The recording will be transcribed and anonymised. The tape will be destroyed immediately after transcription. Individual interviews are expected to last no longer than 20 minutes.

Are there any risks to taking part?

There are no foreseen risks of taking part in this study. The topic of fabricated or induced illness can be a controversial issue. The researcher will seek to ensure sensitivity to the topic during data collection and when considering the appropriateness of wider dissemination.

You are free to withdraw from the study at any time without giving a reason for your decision. All personal identifiers will be anonymised. You can also request for your data to be removed from any analyses up until transcription and anonymization has taken place.

Are there any benefits to taking part?

This project hopes to improve staff confidence and knowledge regarding appropriate management of cases of fabricated or induced illness. It is therefore hoped that clients who attend the service will benefit from increased staff knowledge. Although participation in this will help inform the development of appropriate guidance and information, there are no direct benefits of participation at this stage.



Will my responses be kept confidential?

This study will not involve the disclosure of any personal information. All information gained during interviews will be anonymised and kept confidential. The audio recordings from interviews will be destroyed after transcription.

Participants' identifying information (e.g. names) will be kept on a separate, password protected, database. Each participant will be allocated a unique identification number, which will link their transcribed responses with their personal information.

What happens to my responses after the study?

Transcribed data will be stored in accordance with the Data Protection Act (1998). This information will be stored for a maximum of 5 years after completion of the study. During this time you can withdraw from the study and request your responses to be returned to you. After this time all paper information will be shredded and only anonymous numerical data will be retained.

What happens to the results of the study?

Information gathered from this study will be used to inform the development of guidance and recommendations for the management of fabricated or induced illness within a Paediatric Chronic Fatigue Syndrome service. Findings will be fed back to the team verbally or, if requested, in the form of an anonymised general summary. This project will also be written up and submitted for assessment as part of the project coordinator's Doctorate in Clinical Psychology, part of this may include submission to an academic journal for peer review and publication

Who can I contact if I have questions?

The project coordinator should be the first point of call:

Email Hannah Rapley h.rapley@bath.ac.uk

The second project coordinators can also be contacted:

Dr Sophie Velleman on sophievelleman@nhs.net Or Maria Loades on m.e.loades@bath.ac.uk

If you have any queries or concerns regarding this research and would rather speak to someone who is not an NHS employee, please contact Professor Paul Salkovskis, programme director form the Clinical Psychology Doctorate, University of Bath (p.m.salkovskis@bath.ac.uk).

Appendix E. Consent Form

Appendix B and C: Participant Information and Consent forms.

Consent form



Participant Identification Number: _____

RESEARCH CONSENT FORM

Title of Project:

Name of Project Coordinators: Hannah Rapley, University of Bath
Dr Maria Loades, University of Bath
Dr Sophie Velleman, Paediatric Chronic Fatigue Service

*Please initial each
white box to indicate
you have read and
agreed to points below*

1. I confirm that I have read and understand the information sheet.
2. I confirm that I have had the opportunity to ask any questions relating to the study.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected.
4. I understand that my data will be anonymised and securely stored in accordance with the Data Protection Act (1998).
5. I understand that the responses I provide will be used to audit staff's confidence and ability working with cases of fabricated or induced illnesses and inform the development of guidance for appropriate management.
6. I consent to my responses from interview to be audio recorded and transcribed. I understand that the transcription will be anonymised and the original tape recording will be destroyed immediately after transcription.
7. I understand that the data I provide will be written up into an anonymised report that will be submitted for assessment as part of the project coordinators Doctorate in Clinical Psychology, and if suitable, to a peer review journal for publication.
8. I give my permission for the results of this study to be verified by other researchers at the University of Bath, which would require them to access my anonymised data.
9. I agree to take part in an interview and complete the questionnaire for the above study.

Name of Participant

Date

Signature

Appendix F. Debriefing Sheet



Debrief Sheet

Improving management of fabricated or induced illness in a paediatric chronic fatigue service: a service improvement project

Thank you very much for taking part in the research.

This service improvement project seeks to understand current practices regarding fabricated or induced illness within your service, and aims to improve the management of these cases. The study involves asking staff about current knowledge of fabricated or induced illnesses (FII), experience working with these cases, and how cases are currently managed and supported. This project hopes to understand the challenges of working with suspected cases of fabricated or induced illness within a Paediatric Chronic Fatigue Syndrome service and therefore hopes to improve staff confidence and knowledge regarding the appropriate management of cases of fabricated or induced illness.

Data storage

All data gained during interviews will be anonymised and kept confidential. The audio recordings from interviews will be transcribed and all personal identifiers will be anonymised. Recordings will be destroyed after transcription. Participants identifying information (e.g. names) will be kept on a separate, password protected database. Each participant will be allocated a unique identification number, which will link their transcribed responses with their personal information. Transcribed data will be stored in accordance with the Data Protection Act (1998). This information will be stored for a maximum of 5 years after completion of the study.

You have the right to withdraw from the study without giving a reason for your decision. You can request for your data to be removed from any analyses up until transcription and anonymisation has taken place

What happens to the results of the study?

Information gathered from this study will be used to inform the development of recommendations for the management of fabricated or induced illness within a Paediatric Chronic Fatigue Syndrome service. Findings will be fed back verbally to the team, and if requested in the form of an anonymised report. This project will also be written up and submitted for assessment as part of the project coordinator's doctorate in Clinical Psychology, part of this may include submission to an academic journal for peer review and publication.

Who can I contact if I have questions?

If you have any questions you can contact the project coordinator, Hannah Rapley, on h.rapley@bath.ac.uk. As a second point of call, the second project coordinator, Maria Loades can be contacted on m.e.loades@bath.ac.uk.

Thank you again for your participation.

Appendix G. Presentation to service



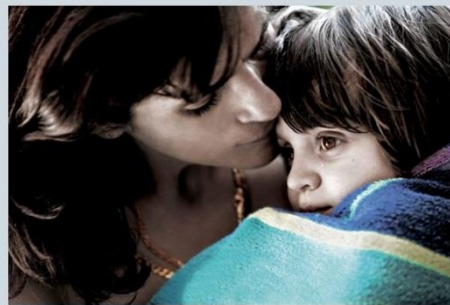
How can we get better at recognising cases of fabricated illness?

A SERVICE IMPROVEMENT PROJECT

HANNAH RAPLEY
CLINICAL PSYCHOLOGIST IN TRAINING
UNIVERSITY OF BATH

SUPERVISED BY DR MARIA LOADES & DR AMANDA LAFFAN

What do we mean by fabricated illness?



What do we mean by fabricated illness?



Why look at this?

- Rare form of child maltreatment
- Difficult for clinicians to recognise and respond to appropriately, therefore can often go unrecognised
- Such rarity and complexity often means clinicians do not feel confident in their ability to identify and manage such cases
- Can occur across all health conditions
- But if occurs in a CFS/ME context may present particular challenges or difficulties

What could be particularly tricky about looking at fabricated illness and CFS/ME?

About the project

Aims:

- Gather information about staff experiences of fabricated or induced illness (FII)
- Understand more about staff knowledge and confidence working with FII
- Understand particular difficulties in recognising and managing FII within this setting
- Gather information about practices regarding FII

What we did?

Interviewed 8 staff

Questions about:

- Knowledge of FII
- Experience of FII
- Recommendations for management of cases where FII is suspected

Transcripts were analysed using thematic analysis (Braun & Clark, 2006)

What was found

2 themes identified:

- Challenges of working when FII is suspected
- Things that can help when FII is suspected

Challenges

Relationship and communication with family

Misunderstandings about FII

Attitudes and understanding of CFS/ME

Difficulties maintaining a therapeutic relationship

Withholding information from the family

Hearing the voice of the child

Knowledge about FII

Disentangling CFS/ME and FII

What helps

Working with others

Practical considerations

Teamwork

Mentors

Liaising with other services

Documentation

Guidelines

What does this mean?

Knowledge, confidence, and experience amongst team members in recognising and acting on concerns of FII was varied.

Several challenges identified are shared in the literature across the other health conditions, when FII is considered.

But, some of the challenges identified are likely unique to working within a CFS/ME context.

Recommendations

Difficulties identified	Recommendations
Varying levels of staff confidence and knowledge about FII	Training about FII. Specific areas that may be useful, include the nature of FII, prevalence rates, and important signs to be alert for
Varying levels of staff experience of FII	Case discussion, possibly facilitated by experienced members of staff
Lack of clarity about guidelines and procedures for FII	Clarification and clear guidance on referral pathways. Familiarization with relevant guidelines regarding FII, e.g. Royal College of Paediatrics and Child Health (2008), Department for Children, Schools, and Families (2009)
Team working, communication and support from colleagues highlighted as crucial when there are concerns about FII	Consideration by the service regarding how to maintain this within an expanding service, composed of multiple satellite sites
Cases where there are concerns about FII can often be demanding on time, and emotionally demanding	Ensuring support structures are in place to ensure staff are appropriately supported when managing demanding cases

What next?



Appendix H. Ethical approval (Study 1 and 2)

Nathalia Gjersoe

Tue 13/09/2016 13:25

Inbox

To:

Hannah Rapley;

You replied on 27/09/2016 17:58.

Dear Hannah Rapley,

Reference number 16-210: Does use of self-harm websites alleviate or exacerbate urges to self-harm?

The ethics committee have considered your application for the study above and have given it conditional ethical approval.

The committee have raised the following points which they would like you to attend to before giving the study full ethical approval:

- The risks have been carefully considered and appropriate action has been planned. The researcher has the relevant skills and expertise to deal with problems. One concern is that participants might reasonably be expecting to be helped in some way rather than just taking part in an experiment.
 - ☐ Modify the information sheet and consent form to address this. For example, either by emphasizing this is research only and not providing treatment, or noting the treatment that is being provided.
 - ☐ Provide an example of the text you will use for the online advertisements or posters including statements addressing this concern.

Please send the revised document to me - you can do this by email to the Ethics Committee: psychology-ethics@bath.ac.uk

Please remember that you may not collect any data until you have ethical approval.

Yours sincerely

Dr Nathalia Gjersoe

Chair, Psychology Research Ethics Committee

psychology-ethics

Thu 29/09/2016 10:27

Inbox

To:

Hannah Rapley;

Dear Hannah,

Thank you very much for making those amendments. I am happy to approve these via Chairs Action.

Best of luck with your data collection,

Dr. Nathalia Gjersoe

Ethics Committee Chair

psychology-ethics@bath.ac.uk>

Fri 10/03/2017 13:01

Inbox

To:

Hannah Rapley;

Dear Hannah Rapley,

Reference Number 16-037: Investigating the use (or not) of self-harm websites by those who self-harm.

The committee have raised the following points which they would like you to attend to before giving the study full ethical approval:

1) Your demographic question in the survey about ethnicity is oddly worded and appears to be somewhat integrating ethnicity and nationality and potentially race together within one question? What type of information are you looking to obtain in the question here (i.e. is it nationality or ethnicity?) and please revise as necessary.

Please reply to this email with the required information. Please follow the instructions on the Psychology Ethics Moodle page to do this:

All amendments must be noted on the application form and highlighted in yellow,

The amended ethics application should be attached to your response

The ethics code should be preserved in the subject line of the email and

Your cover email should detail how you have responded to each point.

Please remember that you may not collect any data until you have ethical approval.

Best wishes,

The Psychology Ethics Committee

psychology-ethics@bath.ac.uk

Tue 14/03/2017 10:33

Inbox

To:

Hannah Rapley;

Dear Hannah,

Thank you for making these amendments. I am happy to confirm that you have been given full ethical approval.

Best of luck with your research,

Dr. Nathalia Gjersoe

Chair, Psychology Ethics Committee

Appendix I. Risk assessment

Risk Assessment Guidance

The assessor can assign values for the hazard severity (a) and likelihood of occurrence (b) (taking into account the frequency and duration of exposure) on a scale of 1 to 5, then multiply them together to give the rating band:



Hazard Severity (a)	Likelihood of Occurrence (b)
1 – Trivial (eg discomfort, slight bruising, self-help recovery)	1 – Remote (almost never)
2 – Minor (eg small cut, abrasion, basic first aid need)	2 – Unlikely (occurs rarely)
3 – Moderate (eg strain, sprain, incapacitation > 3 days)	3 – Possible (could occur, but uncommon)
4 – Serious (eg fracture, hospitalisation > 24 hrs, incapacitation > 4 weeks)	4 – Likely (recurrent but not frequent)
5 – Fatal (single or multiple)	5 – Very likely (occurs frequently)

The risk rating (high, medium or low) indicates the level of response required to be taken when designing the action plan.

Rating Bands (a x b)	
LOW RISK (1 – 8)	MEDIUM RISK (9 – 12)
Continue, but review periodically to ensure controls remain effective	Continue, but implement additional reasonably practicable controls where possible and monitor regularly
Remote	Unlikely
Possible	Likely
Very likely	Very likely
Trivial	Minor
Moderate	Serious
Fatal	Fatal

UOB Risk Assessment

University Health, Safety & Environment Unit

Risk Assessment Record

Risk Assessment of: Participants leaving research study	Assessor(s): Hannah Rapley	Date: 28/08/16
Overview of activity / location / equipment / conditions being assessed:	Research study investigating effects of use of self-harm related websites on thoughts and feelings of self-harm.	
Generic or specific assessment? Specific assessment	Context of assessment (delete as appropriate): planning stage / 'desk-top' exercise / site visit / in consultation with employees / in consultation with managers / other (please describe)	

#	Hazard(s) identified	Persons affected	Existing controls & measures	A	B	A x B	Additional controls required
1	Exposing participants to potentially triggering content on self-harm websites	Participants	<ul style="list-style-type: none"> Participants will be asked to choose to view a website that they have previously accessed. Therefore, they will not be exposed to any new material by taking part in the study. 	2	3	6	
2	Participant has urge to self-harm during the study	Participants	<ul style="list-style-type: none"> Prior to entering the study participants will be asked about their coping strategies for managing self-harm. These will be drawn upon if this occurs. Urges to self-harm will be documented during the study, the researcher will therefore be able to monitor this. If a participant becomes unduly distressed and it is deemed by the research to be unsuitable or unsafe to continue, the study will be discontinued. A relaxation exercise will be offered to the participant upon completion of the study. This will aim to lower participant's affect and self-harming urges. The study will be conducted in the University of Bath's Department of Psychology, if required, the researcher can contact their supervisor or other Clinical Psychology staff to assist. 	2	3	6	

#	Hazard(s) identified	Persons affected	Existing controls & measures	A	B	A x B	Additional controls required
3	Participant has urge to self-harm after leaving the study		<ul style="list-style-type: none"> A relaxation exercise will be offered to the participant upon completion of the study. This will aim to lower the participant's affects and self-harming urges. Participants will be provided with a debriefing sheet. On this sheet will be contact details of services available to support them. A list of coping strategies to help participants manage urges to self-harm will be provided. Participants are required to fill out on the consent form contact details of their GP and/or any mental health services they are supported by. They will be informed that should the researcher be particularly concerned about their welfare, their GP or other named support will be contacted. This will be done in the presence of the participant. 	2	3	6	
4	Participant has suicidal ideation or plans		<ul style="list-style-type: none"> Should this be evident prior to the participant entering the study the researcher will not enter the participant into the study. Full debriefing procedure will still be applied Researcher conduct a full risk assessment of their suicidal ideation. The participant's GP or mental health services will be contacted immediately in the presence of the participant. A plan for the participant exiting the study will be drawn up with them. 	5	1	1	
5	Researcher viewing distressing material on websites		<ul style="list-style-type: none"> Supervision will be sought should this occur. 	1	3	3	
	Assessor signature:		Print name:	Review date:			

☐

Appendix J. Information and Consent (Study 1 and 2)

PARTICIPANT INFORMATION SHEET:

The impact of self-harm websites on viewers

You are invited to take part in a research project which is investigating the effects of self-harming websites on self-harming thoughts and behaviours. The following information sheet gives details about the project and explains what will be involved if you choose to participate. Please read this sheet carefully before deciding whether you would like to take part. If you have any questions, please contact the project coordinator, Hannah Rapley at h.rapley@bath.ac.uk.

What is the purpose of this study?

This research project seeks to understand the effects that use of self-harm related websites has on self-harming thoughts, feelings and behaviours. Websites containing self-harm related material have grown hugely in the last few years and are places in which users can discuss and share their experiences related to self-harm. Research asking website-users about why they access these websites has revealed that these websites can have both potential positive and negative effects.

However, no research has yet looked at people's thoughts, feelings and behaviours *whilst* they look at these websites.

What will be asked of me if I choose to take part?

You will be asked to attend the University of Bath, where the researcher will remind you what the research would include.

You will be asked to spend up to 10-15 minutes looking at a website which is related to self-harm. The website you choose to look at is up to you, the researcher will ask you to pick a website that you already look at, perhaps the one you use most often.

You will be asked to complete some questionnaires both before you go on the website and afterwards. The questionnaires will ask about your mood, social support and thoughts about self-harm. You will also be asked to fill in some information about your use of self-harm websites and about any self-harming behaviours you do.

At the end of the study, you will be asked to take part in a short relaxation exercise. This is up to you: if you think it would be helpful you can choose to take part, but you do not have to.

The total time for participation in this study is expected to be 40 minutes.

Your rights as a research participant.

Participation in this study is voluntary. You have the right not to participate. You are free to withdraw from the study at any time without giving reason for your decision. You have the right to ask that any data supplied to that point to be withdrawn/destroyed.

Feel free to ask questions at any point. If you have any questions as a result of reading this information sheet you should ask the researcher before the study begins.

Are there any risks to taking part?

This study asks participants to look at a website containing self-harm related material. There may be risks associated with this: by looking at self-harm material online participants may feel 'triggered', which could increase their psychological distress and their desire and likelihood to self-harm.

Several steps have been taken to minimise and manage these risks, including:

- The researcher will ask you to view a website that you have previously used, perhaps the one that you go on most often. This means that you will be able to choose what you look at, and will not be asked to view any new materials that you have not seen before.
- You will be asked to fill in the contact details of your GP or health service when filling in the consent form. Your GP (or health service key worker) will not be contacted unless the researcher is particularly concerned for your safety during or following the completion of the study. The researcher will let you know if they would like to contact your GP (or health service key worker) and will do this with you.
- Once you have taken part in the study, the researcher will ask if you would like to take part in a 10 minute relaxation exercise, this is optional.
- When you have finished the study you will be provided with some information on services available to support you and coping strategies that others have found useful.

Are there any benefits to taking part?

This project hope to understand more about self-harm websites and how they affect people's self-harming thoughts and behaviours. By taking part in this research you will be contributing to knowledge about this topic. It is hoped that the results of this study can inform healthcare professionals working with people who self-harm on the risks and benefits of such websites.

Taking part in this research does not enable access to treatment, but the researcher can provide information on available services for support.

As a thank you for participating in this study we are able to offer a £5 shopping voucher for each participant.

We are also able to travel expenses to and from the University of Bath, up to a maximum of £15. You will need to provide receipts of your travel.

Will my responses be kept confidential?

All information from the study will be anonymised and kept confidential. The information you provide will be given an identification number and will not contain your name.

Your name, contact details and GP details will be asked for on the consent form only. This will be stored separately and securely from the research data. Therefore, no information will be identifiable to you.

What happens to my responses after the study?

Data will be stored in accordance with the Data Protection Act (1998). The information will be stored in locked cabinets within the psychology department. Consent forms which include participants' names will be stored separately to the information you give during the study. Only the researcher and her supervisor will have access to the data. This information will be stored for 10 years after the completion of the study (as required by British Psychological Society regulations). After this time all electronic and paper information will be shredded and only anonymous numerical data will be retained.

What happens to the results of the study?

This project will be written up and submitted for assessment as part of the researcher's Doctorate in Clinical Psychology. This may include submission to an academic journal for peer review and publication. No identifiable information will be included in this and data will be presented for all participants as a whole.

Who can I contact if I have questions?

The researcher, Hannah, will be happy to answer your questions about this study at the time, and if you would like she can inform you about the results of the study once the data collection is complete. You may contact her on h.rapley@bath.ac.uk.

RESEARCH CONSENT FORM: **The impact of self-harm websites on viewers**

Project coordinator: Hannah Rapley

By signing this consent form, I am confirming and agreeing to the following:

1. I have read and understand the Participant Information Sheet.
2. I have had the opportunity to ask questions relating to the study.
3. I understand my participation is for research purposes.
4. I have been informed of any potential risks of participating in this study.
5. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.
6. I understand that the information I provide will be stored anonymously and securely in accordance with the Data Protection Act (1998).
7. I understand that the information I provide will be included in a research paper that will be submitted for assessment as part of the project coordinator's Doctorate in Clinical Psychology, and if suitable, to a peer review journal for publication.
8. I agree to take part in the research for the above study.

*Please
initial
each box*

Name of Participant (*Printed*)*

Signature

Date

Name of Researcher

Signature

**Participants wishing to preserve some degree of anonymity may use their initials (from the British Psychological Society Guidelines for Minimal Standards of Ethical Approval in Psychological Research)*

Please turn over.

The following contact details are required.

The people below will not be contacted, unless the researcher is significantly concerned for your safety and wellbeing.

Please provide details of your:

GP: Name _____
Surgery _____

Contact number (*if known*) _____

Are you currently under the care of any mental health services? YES/ NO (*please circle one*)

If so, please provide the name of:

The service

The name of the lead professional you are working with

Contact number (*if known*)

GPs or other health professionals will not routinely be contacted about your participation in this study. They will only be contacted by the researcher if sufficient concern arises during the course of the study. The researcher will inform you if she would like to contact them.



Self-harm in Social media: A research project

This study is investigating the thoughts, feelings and behaviours of people who self-harm. It is looking at why some people who self-harm look at self-harm material online, and why others do not.

Social media and websites containing self-harm related material have grown hugely in the last few years and are places in which users can view and share experiences related to self-harm. Research has shown that this can have both helpful and unhelpful effects on people. However, no research has yet looked at why some people look at this material online, and others do not.

This study is asking young adults who self-harm to take part in a survey.

You are eligible to take part in this study if:

- You are between 17-25 years old
- And you self-harm

If you choose to take part, you will be asked to complete questions about your thoughts, feelings and self-harming behaviours.

In total, your participation will take about 20 minutes.

It is important that only people who self-harm take part.

You can find more information about the study [here](#).

If you have any questions, you can contact the lead researcher, Hannah Rapley, at socialmediaresearch@bath.ac.uk

If you are interested in taking part, and fit the criteria, please click onto the next page. Please answer all questions in the survey.



If the boxes below apply to you, please select them to take part in the study.

Please select the boxes below

I am over 16 years old

☐

I understand what is
involved with taking
part in this study

☐

I consent to taking part
in this research

☐

Please enter your date of birth:

Day

Month

Year

>>

Appendix K. Debriefing information (Study 1 and 2)

DEBRIEFING SHEET:

The impact of self-harm websites on viewers



Thank you very much for taking part in this research project.

This study seeks to understand the effects that use of self-harm related websites can have on self-harming thoughts, feelings and behaviours. Self-harm related websites contain a wide range of material, where individuals can discuss and share experiences related to self-harm. Recent research has shown that people use these websites to support their recovery, but also to encourage themselves to engage in further self-harm. This study sought to look at how thoughts and feelings related to self-harm change when people look at these websites.

Who can I contact if I am feeling low in mood?



Below are a list of services that you contact if you are feeling low in mood:

- **Childline: 0800 111** or you can talk online on www.childline.org.uk
“Childline is a free, private and confidential service where you can be you. Whatever you need help, however you want to get in touch. We’re here for you online, on the phone, anytime” (for under 19s).
- **Samaritans: 08457 90 90 90** 
Confidential emotional support for anyone, using their 24-hour helpline.
- **RecoverYourLife.com**
This is an online community where you can get peer support for self-harm and other mental health problems.
- **Support Line: 0208 554 9004**
A confidential helpline providing emotional support to individuals of any age on any issue. They also have a database of local services.
- **CASS (Confidential anonymous self-injury support): 0808 800 8088** 
Women’s self-injury helpline. Text and email support services (TESS) also available on 0780 047 2908 and www.selfinjurysupport.org.uk
- **Nightline** (for university students) 
National organisation of Nightline student helplines in universities across the UK. Visit the website to find out if your university has one: www.nightline.ac.uk.
- If you feel like you would like support from mental health services, your **GP** would be able to talk to you about this.

What can I do if I want to self-harm?

When you're feeling emotions that make you want to self-harm it is good to find other ways of coping. You might already have your own coping strategies that you use when you are feeling low or are wanting to self-harm. Below is a list of some strategies that others have found useful:

- Listening to music
- Talking to friends and family
- Writing down or drawing how you feel
- Exercise
- Have a bath or shower
- Use breathing and relaxation exercises
- Make a list of activities that you can use to distract yourself
- Spend time with other people to distract yourself from urges to self-harm
- Squeeze an ice cube in your hand
- Put elastic bands on your wrist, arms or legs, and flick them instead of cutting or hitting
- Use a red felt tip pen to mark where you might usually cut, instead of cutting

Data storage

All information gathering as part of this study will be anonymised and kept confidential, in accordance with the Data Protection Act (1998). It will be stored in locked cabinets in the psychology department, and only be accessible to the researcher and their supervisor. No personal information will be stored that could identify you.

What happens to the results of the study?

Information gathered from this study will be included in a project that will be submitted for assessment as part of the researcher's Doctorate in Clinical Psychology. This may include submission to an academic journal for peer review and publication. No identifiable information will be included in this.

Who can I contact if I have questions?

At the end of the study please feel free to ask questions of the project coordinator. If you have any questions after you have left, you can contact the project coordinator at h.rapley@bath.ac.uk.

Thank you again for your participation.



Thank you for taking part in this study.

Your time and answers are appreciated, and will contribute towards research on self-harm and the effects of looking at self-harm online.

If you want more information about the research, please look at the study's [website](#).

If you have any further questions about the research, you can contact the researcher on socialmediaresearch@bath.ac.uk

Below are a list of services that you can contact if you are feeling low in mood:

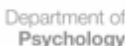

- **Childline: 0800 111:** or you can talk online on www.childline.org.uk. "Childline is a free, private and confidential service where you can be you. Whatever you need help with, however you want to get in touch. We're here for you online, on the phone, anytime" (for under 19s)
- **Samaritans: 08457 90 90 90:** Confidential emotional support for anyone, using their 24-hour helpline.
- **RecoverYourLife.com:** This is an online community where you can get peer support for self-harm and other mental health problems.
- **Support Line: 0208 554 9004:** A confidential helpline providing emotional support to individuals of any age on any issue. They also have a database of local services.
- **CASS (Confidential Anonymous Self-injury Support): 0808 800 8088:** Women's self-injury helpline. Text and email support services (TESS) also available on 0780 047 2908 and www.selfinjurysupport.org.uk
- **Nightline (for university students):** National organisation of student helplines in universities across the UK. Visit the website to find out if your university has one: www.nightline.ac.uk
- If you feel you would like support from mental health services, your GP would be able to talk to you about this.

You might already have your own strategies that you use when you are feeling low or are wanting to self-harm. Below are a list of some strategies that others have found useful:

- Listening to music
- Talking to friends and family
- Writing down or drawing how you feel
- Exercise
- Have a bath or shower
- Use breathing and relaxation exercises
- Make a list of activities that you can use to distract yourself
- Spend time with other people to distract yourself from urges to self-harm
- Squeeze an ice cube in your hand
- Put elastic bands on your wrist, arms, or legs and flick them instead of cutting or hitting
- Use a red felt tip pen to mark where you might usually cut, instead of cutting

If you would like to listen to a relaxation exercise now, please click [here](#).

Appendix L. Recruitment poster

Opportunity to participate in research study.


The impact of self-harm websites on viewers

Why are we doing this research?

The use of self-harm related websites has grown hugely. This research wants to understand how the use of these websites impacts on thoughts, feelings and behaviours.

What is involved if I take part?

You will be asked to attend the University of Bath Psychology Department to take part in the study. You will be asked to spend 10 minutes looking at a website related to self-harm that you use frequently. You will be asked to complete some questionnaires before and after this task. |




This study has been approved by the Ethics Committee in the Department of Psychology, University of Bath.

I'm interested! What should I do?

You are eligible to take part if you use self-harm related websites, are between 17-25 years old, and are not in your first year of university.

If you are interested in taking part or learning more about the study, please email the researcher Hannah Rapley on h.rapley@bath.ac.uk and you will be sent information about the study.

This research is being undertaken by Hannah Rapley (Clinical Psychologist in training), and Dr Catherine Hamilton-Giachritsis (Clinical Psychologist).



elf-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk	Self-harm websites study Contact: h.rapley@bath.ac.uk
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Appendix M. Visual Analogue Scale of desire to self-harm

Desire to self-harm rating

*Please rate where you currently are on the scale below.
Please rate with a line, and write a number.*



Appendix N. Internal consistency of questionnaire measures as reported by authors

Measure	Cronbach's α	Internal consistency
ABUSI	0.92	Excellent
PHQ-9	0.86	Good
Revised-UCLA	0.96	Excellent
PANAS PA	0.88	Good
PANAS NA	0.85	Good
QPR	0.86	Good

Rating of Note: Internal consistency informed by George and Mallery (2003); $\alpha > 0.9$ = 'excellent', $\alpha > 0.8$ = 'good', $\alpha > 0.7$ = 'acceptable'; ABUSI = Alexian Brothers Urge to Self-Injure Scale, PHQ-9 = Patient Health Questionnaire-9, PANAS = Positive and Negative Affect Scale, PA = Positive Affect, NA = Negative Affect, UCLA = Revised-UCLA Loneliness Scale, QPR = Questionnaire about the Process of Recovery.

Appendix O. Rating of appraisal of online self-harm material viewed:

Please rate the website related to self-harm that you most commonly visit, on the scale below:

1	2	3	4	5
<hr/>				
‘Negative’ e.g. “triggering”, pro self-harm information, advice on methods of self- harm.		‘Neutral’ e.g. provides factual information without explicit preventive or pro-self-harm content.		‘Positive’: e.g. provides helpful information, advice to seek help, or advises against self- harm

Appendix P. Example of online advertisement



Self-harm in Social Media

Published by Hannah Rapley [?] · 16 March ·

We are inviting young adults (aged 17-25) who self-harm to take part in a research project investigating why some people who self-harm look at self-harm material online, and why others do not.

If you self-harm follow the link to the questionnaire:
<https://bathpsychology.eu.qualtrics.com/SE/...>



Appendix Q. Qualitative information on websites and search terms

What website do you use most often to look at self-harm material online?	
<i>Website</i>	<i>Frequency</i>
Tumblr	28
Instagram	28
Google	27
Youtube	7
Twitter	4
Facebook	2
Pinterest	2
Different self-harm forums	2
Whatever sites crosses my path	1
A self-injury section of a pro ana website	1
B.A.S.E website, in Bolton	1
Headspace	1
Myproana	1
BPD forums	1
Livejournal.com	1
7 cup of tea	1

What search terms do you use to look at self-harm material?	
<i>Website</i>	<i>Frequency</i>
Self harm	30
Cutting	26
Depression	10
Self injury	7
SI	3
Deep cuts	3
Self harmmm	3
Blithe	3
Suicidal	3
Blood	3
Suicide	2
SH	2
Self harm scars	2
Scars	2
How to cut deeper	2
Relapse	2
Secretsociety123	2
Trigger warning	2
Hurting	1
Pro self harm	1

Pro self injury	1
Deep self injury	1
Self bruising	1
Bruises	1
Self-harm needles	1
I cut because	1
Why do I self harm	1
How to stop self harm	1
Rape	1
How to prevent self harm	1
How to get over self harm	1
How do you stop the voices	1
How to overdose	1
What's the best way to self harm	1
What's the best way to kill yourself	1
Self harm quotes	1
Thinspo	1
Ana	1
Scarring	1
How to hide cutting	1
Ways of coping	1
Mental health	1
How many tablets to OD	1
Sad	1
Tw destruction	1
BPD	1
Self harm stories	1
Self harm songs/depression songs	1
Subcutaneous cuts	1
Anxiety	1
Loneliness	1
Burning	1
House fire survivor	1
Struck by lightening	1
Mutilation	1
Cut	1
Letting the pain out	1
Thin women	1
Depressed	1
Secretsoceity00	1
Bulimia	1
Anorexia	1

Appendix R. Power analyses: cross-sectional study (Study 2)

Power calculations were run to determine the necessary sample size to detect small, medium and large effects (based on Cohen's *d* statistic)

Effect size (Cohen's <i>d</i>)	Description	Power	α	Required sample size
0.2	Small	0.80	0.05	788
0.5	Medium	0.80	0.05	128
0.8	Large	0.80	0.05	52

On the basis of these calculations, it was intended to power the study to detect medium-sized effects. This required a sample size of $n=128$, corresponding to 64 participants in each group (those who view self-harm and those who do not.)

A post-hoc extension of the power calculation was completed after data collection, to compute the achieved power in this study. Post hoc analyses indicated 63-93% power to detect medium effects in this study.

Analysis	α	Effect size (Cohen's <i>d</i>)	Description	Power
Group comparisons ($N=126$)				
ABUSI	0.05	0.62	Medium	0.92
PHQ-9	0.05	0.41	Medium	0.63
UCLA	0.05	0.62	Medium	0.93
PANAS PA	0.05	0.43	Medium	0.68
PANAS NA	0.05	0.53	Medium	0.84
QPR	0.05	0.61	Medium	0.93

*Note: Power calculations completed using G*Power, effect size=Cohen's *d*, where $d \geq 0.2$ = small, $d \geq 0.5$ = medium, $d \geq 0.8$ =large; ABUSI = Alexian Brothers Urge to Self-Injure Scale, PHQ-9 = Patient Health Questionnaire-9, PANAS = Positive and Negative Affect Scale, PA = Positive Affect, NA = Negative Affect, UCLA = Revised-UCLA Loneliness Scale, QPR= Questionnaire about the Process of Recovery.*

Appendix S. Qualitative analysis plan

Content analysis has been described using a wide range of definitions, here the following definition was considered helpful; content analysis is a “...systematic, replicable data reduction technique, compressing many words of text into content categories based on explicit rules of coding” (Stemler, 2001, p.137). It can be used to identify, trends, patterns and frequencies within textual information and allows for both qualitative analysis and quantifying data (Gbrich, 2007). Guidance by Elo and Kyngas (2008) and Robson and McCartan (2016) was followed.

The data analysed was from two free text boxes on the online questionnaire, these asked: “Why do you view self-harm material online?” and “Why do you not view self-harm material online?” The research question seeking to be answered was: Why do young adults who self-harm view, or do not view self-harm material online? The responses consistent of a brief phrase or sentence. All responses were included in the analysis. Themes were chosen as the unit of analysis. Latent content was examined, and thus coding was carried out in conjunction with the second author as a step to ensure reliability. During the preparation phase the researcher familiarised themselves with the data. Following this the data was organized, coded and themes were created. These themes were then refined and grouped in conjunction with the second author, and named using content-characteristic words. The term ‘theme’ was used instead of ‘categories’ as these groupings were thought to be expressions of the latent, rather than manifest, content (Graneheim & Lundman, 2004)

Appendix T. Statistical analyses and assumptions

All analyses were conducted using SPSS version 20 (IBM Corp., 2011).

Missing data strategy:

The data was examined for missing data. No single item per scale missing data was found. Individual participants with missing data across multiple items per scale were excluded from analyses. Only very few participants were excluded as a result of this approach (n=3) (Tabachnik & Fidell, 2005; Field, 2009).

Tests of normality and variances for continuous variables by group.

	View self-harm material online (n=60)		Do not view self-harm material online (n=66)		All participants (n=126)		
	Skewness	Kurtosis	Skewness	Kurtosis	Skewness	Kurtosis	Levene's test
Age	.657	-.908	-.164	-1.121	.162	-1.302	F=0.54, p=.464
ABUSI	-.724	.118	.237	-.550	-.184	-.727	F=.028, p=.601
PHQ-9	-1.238	.498	-.460	-.861	-.715	-.697	F=5.21, p=.025
PANAS PA	.849	-.088	.429	.084	.631	.011	F=0.21, p=.650
PANAS NA	-.388	.078	-.582	.926	-.649	.982	F=3.06, p=.083
UCLA	-.574	-.504	-.243	-.460	-.374	-.564	F=0.36, p=.548
QPR	-.326	-.660	-.279	-.597	-.199	-.553	F=0.26, p=.609

Note: Approximately normal distributions are indicated by skewness and kurtosis values of 0 ± 1 ; homogeneity of variances is indicated by a Levene's tests where $p > .05$; ABUSI = Alexian Brothers Urge to Self-Injure Scale, PHQ-9 = Patient Health Questionnaire-9, PANAS = Positive and Negative Affect Scale, PA = Positive Affect, NA = Negative Affect,

UCLA = Revised-UCLA Loneliness Scale, QPR = Questionnaire about the Process of Recovery.

Regression Assumptions

Outliers

An analysis of standard residuals was carried out, no outliers were found in the data (Std. Residual Min = -2.139, Std Residual Max = 1.363).

Collinearity

Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern.

Collinearity Statistics		
	Tolerance	VIF
PHQ-9	.357	2.800
PANAS PA	.489	2.045
PANAS NA	.753	1.327
UCLA	.433	2.311
QPR	.218	4.582

Independent Errors

The data met the assumption of independent errors (Durbin-Watson value = 2.175)

Random Normally Distributed Errors

The histogram of standardised residuals indicated that the data contained approximately normally distributed errors, as did the normal P-P plot of standardised residuals, which showed points that were not completely on the line, but close.

Homoscedasticity and Linearity

The scatterplot of standardised residuals showed that the data met the assumptions of homogeneity of variance and linearity.

Non-Zero Variances

The data met the assumption of non-zero variances.

Variable	Variance
ABUSI	53.986
PHQ-9	74.880
PANAS PA	50.897
PANAS NA	53.848
UCLA	102.858
QPR	260.399

Appendix U. Demographic information for collapsed groups

Do not view online (<i>n</i>=66)		
	Never viewed (<i>N</i> =37)	Previously viewed (<i>N</i> =29)
	Mean (SD)	Mean (SD)
Sample characteristics		
Age	21.50 (2.39)	21.45 (2.77)
Gender	91.9% female	92.9% female
Nationality	87.1% British	60.0% British
Ethnicity	94.6% Caucasian	89.7% Caucasian
Contact with mental health services	70.3%	62.1%
Mental health diagnoses		
Depression	67.6%	65.5%
Anxiety	54.1%	62.1%
BPD	40.5%	51.7%
PTSD	29.8%	17.2%
Eating disorder	21.6%	10.3%
Bipolar disorder	5.4%	13.8%
OCD	10.8%	6.9%
Psychosis	2.7%	6.9%
Types of self-harm		
Cutting	97.3%	93.1%
Interfering with wound healing	40.5%	41.4%
Severe scratching	51.4%	44.8%
Burning	27.0%	24.1%
Pinching	18.9%	27.6%
Hair pulling	21.6%	31.0%
Biting	18.9%	24.1%
Swallowing dangerous substances	18.9%	24.1%
Sticking self with needles	2.7%	6.9%
Carving	2.7%	10.3%
Number of methods of self-harm used	3.00 (1.29)	3.28 (1.83)

Appendix V. Demographic information

Demographic		Number
Gender	Female	118
	Male	3
	Transgender	3
	Prefer not to say	2
Nationality	British	66
	American	15
	Australian	8
	Canadian	6
	New Zealand	4
	German	1
	Dutch	1
	South African	1
	Indonesian	1
	Romanian	1
	Malaysian	1
	Saudi Arabian	1
	Sri Lankan	1
	Polish	1
Ethnicity	Caucasian	116
	Black/African	1
	Asian	3
	Arab	1
	Mixed/multiple ethnicities	5
	Other	0
Employment status	Employed	28
	Unemployed	40
	Student	52
	Volunteer	6

Appendix W. Correlation matrix

	ABUSI	PHQ-9	PANAS PA	PANAS NA	UCLA	QPR
ABUSI	-	-	-	-	-	-
PHQ-9	.207	-	-	-	-	-
PANAS PA	-.088	-.666**	-	-	-	-
PANAS NA	.322*	.432**	-.236	-	-	-
UCLA	.248	.551**	-.387**	.354**	-	-
QPR	-.192	-.771**	.697**	-.304*	-.716**	-

*Note: * $p \leq .05$, ** $p \leq .01$; ABUSI = Alexian Brothers Urge to Self-Injure Scale; PHQ-9 = Patient Health Questionnaire-9; PANAS = Positive and Negative Affect Scale; PA = Positive Affect; NA = Negative Affect; UCLA = Revised-UCLA Loneliness Scale; SWEMWBS = Short Warwick-Edinburgh Mental Wellbeing Scale; QPR = Questionnaire about the Process of Recovery; *higher scores indicate worse functioning; ** higher scores represent better functioning*

Appendix X. Visual depictions of themes from thematic analysis

